

COPING STRATEGIES, SOCIAL SUPPORT, AND SELF-CARE AMONG YOUNG
WOMEN WITH PELVIC INFLAMMATORY DISEASE

by

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ABSTRACT

Pelvic inflammatory disease (PID), a spectrum of inflammatory disorders of the female upper genital tract, is a serious complication of sexually transmitted infections (STIs) that may lead to chronic pelvic pain, ectopic pregnancy, and tubal infertility. Although PID treatment is critical for the preservation of fertility and health-related quality of life, many young women diagnosed with PID do not fully adhere to treatment recommendations. Interventions focused on clinician practices, patient education, and behavioral modeling have generated limited improvements in outpatient PID treatment adherence among young women, thereby suggesting the influence of other determinants, such as psychosocial factors. Coping and social support are psychosocial factors that may affect PID self-management. A comprehensive literature review revealed a dearth of published research focused on coping with PID and related social support among young women. Guided by the Transactional Model of Stress and Coping, this dissertation study used a convergent mixed methods design to examine and explore the coping strategies, social support, and self-management behaviors (medication completion, clinical follow-up visit attendance, partner notification, and sexual abstinence) of 90 young women during the PID treatment period. Study participants comprised a subsample of young women enrolled in a randomized controlled trial of an outpatient intervention designed to reduce adverse outcomes after PID. Quantitative data were collected via audio computer-assisted self-interview and structured in-person interviews. Qualitative data collection consisted of semi-structured interviews with 18 participants to explore the experiences of young women diagnosed with and treated for PID. Quantitative results indicated that the social provision of opportunity for nurturance (perceived responsibility for others) was positively associated with medication completion

(AOR=1.26, 95% CI: 1.00-1.59, $p=0.05$) and clinical visit attendance (AOR=2.43, 95% CI: 1.19-4.93, $p=0.01$). Qualitative findings revealed that upon learning about their diagnosis, young women were self-motivated to ameliorate PID. With support from family and friends, they incorporated PID self-management into their daily lives—which may not have been fully consistent with prescribed medical protocols. In conclusion, social support is associated with PID self-management among young women. Assessing young women’s coping and social support resources can inform a tailored plan for successful PID treatment.

Advisor: Phyllis Sharps, PhD, RN, FAAN

PREFACE

This dissertation is dedicated to my mother, Linda Tillman, and my brother, Juan Tillman, whose immense support made it possible for me to relocate from South Carolina to Maryland to pursue my dream of earning a PhD from Johns Hopkins University.

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CHAPTER ONE: INTRODUCTION

Background

Each year, approximately 800,000 cases of pelvic inflammatory disease (PID) are diagnosed in the United States (Greydanus & Dodich, 2015). Between 2006 and 2010, an estimated 2.6 million reproductive-aged women reported receipt of PID treatment in their lifetime (Leichliter, Chandra, & Aral, 2013). PID comprises a spectrum of inflammatory disorders of the female upper genital tract, including salpingitis, endometritis, tubo-ovarian abscess, and pelvic peritonitis (Centers for Disease Control and Prevention, 2015; Handsfield, 2011). Arising from an ascending genital infection unrelated to childbirth or invasive procedures of the genital tract, PID is a serious complication of sexually transmitted infections (STIs). At least 90% of primary episodes of PID are sexually acquired; few cases are attributed to non-sexually transmitted pathogens (Handsfield, 2011). Sexually transmitted organisms, such as *Neisseria gonorrhoeae* (GC) and *Chlamydia trachomatis* (CT), are involved in many PID cases (Centers for Disease Control and Prevention, 2015; Handsfield, 2011). CT is the most common cause of acute PID in industrialized countries, and probably the cause of most subclinical cases. GC is a major cause of PID in populations and geographic settings where gonorrhea is common (Handsfield, 2011).

Although PID is an acute disease, poorly managed PID has significant chronic implications; women with PID may develop chronic pelvic pain, ectopic pregnancy, and tubal infertility (Brunham, Gottlieb, & Paavonen, 2015; Greydanus & Dodich, 2015). At least 20% of PID cases occur in adolescents (Greydanus & Dodich, 2015), who are at increased risk for subsequent STIs and PID (A. M. Kelly, Ireland, & Aughey, 2004; Trent, Chung, Forrest, & Ellen, 2008; Trent et al., 2011; Trent, 2013b). Because PID is commonly caused

by untreated STIs, STI treatment and prevention are critical for the preservation of fertility and health-related quality of life among young women diagnosed with PID (Brunham et al., 2015; Greydanus & Dodich, 2015).

PID Management

The results of the Pelvic Inflammatory Disease Evaluation and Clinical Health (PEACH) study, a large, multisite randomized clinical trial and related cost-effectiveness analyses recently shifted treatment of mild to moderate PID from inpatient care to the outpatient setting (Smith, Cook, & Ness, 2007; Smith, Ness, & Roberts, 2007; Smith, Ness, Wiesenfeld, & Roberts, 2007; Smith, Tsevat, Ness, Wiesenfeld, & Roberts, 2008). The current standard of care for treatment of mild to moderate PID includes a 14-day course of outpatient oral antibiotic therapy and pain management, partner notification for treatment, sexual abstinence until patient and partner are treated, and a follow-up evaluation within 72 hours (Centers for Disease Control and Prevention, 2015). Consistent condom use at the resumption of sexual intercourse reduces the risk for STI reinfection and new PID occurrences; after adjustment for covariates such as age, race, nonmonogamy at baseline, new partner at baseline, GC or CT at baseline, and use of other forms of contraception, the relative risk for recurrent PID among consistent condom users compared with nonusers was 0.5 (95% CI: 0.3-0.9) (Ness et al., 2004).

Although large randomized clinical trials such as the PEACH study have demonstrated that more expensive inpatient antibiotic treatment does not afford additional clinical efficacy compared to outpatient antibiotic treatment for mild to moderate PID (Ness et al., 2002), adherence to the Centers for Disease Control and Prevention (CDC)-recommended outpatient treatment regimen among young women (i.e., adolescent girls and

young adult women 13 to 25 years old) remains suboptimal (Trent, 2013b). The longitudinal outcomes of clinical trials suggest that outpatient PID treatment presents significant self-care or self-management challenges for young women. Within seven years of PEACH study enrollment, over 20% of women had recurrent PID. Many young women diagnosed with PID do not achieve full adherence to CDC treatment recommendations (A. M. Kelly et al., 2004; Trent et al., 2011). Medication adherence measured by electronic event monitoring in a subgroup of PEACH study participants demonstrated that women took an average of 70% of prescribed doses of doxycycline, took the prescribed two daily doses for less than 50% of outpatient treatment days, and took only 16.9% of doses within the optimal timing interval (Dunbar-Jacob, Sereika, Foley, Bass, & Ness, 2004). Approximately 29% of PEACH study participants reported that their partners received STI treatment after their PID diagnosis, and approximately 15% reported failure to abstain from sexual intercourse during the PID treatment period (Trent et al., 2011).

A retrospective chart review of adolescents diagnosed with PID at an urban teen clinic revealed that 47% of those adolescents had at least one additional prior or subsequent episode of PID. Only 36% reported that their partners received STI treatment. Clinical documentation suggested that 23% of patients did not adhere to the medication regimen and sexual abstinence recommendations. Compared to girls with recurrent episodes of PID, girls with only one PID episode were 1.44 times more likely to report adherence to treatment recommendations. Girls with only one episode of PID were 2.47 times more likely than their counterparts with recurrent PID to always report that their partners had been treated. Sixty percent of girls with recurrent PID never reported that their partners received treatment, and 13% always reported that their partner had been treated. Although retrospective chart reviews

have limitations dependent upon the accuracy and thoroughness of clinical documentation and patient self-report, study results suggest that adolescents with recurrent PID were less adherent to treatment and self-care recommendations than their single-episode peers (A. M. Kelly et al., 2004).

Compared to their older counterparts, young women diagnosed with PID are at increased risk for subsequent STIs and PID, and adverse reproductive health outcomes (Trent et al., 2008; Trent et al., 2011; Trent, 2013b). At 30-day follow-up, 20% of adolescent PEACH study participants tested positive for an STI, compared to 5.2% of adult participants (Trent et al., 2011). In a separate study of adolescents who received outpatient treatment for PID, 34% were diagnosed with CT, GC, and/or PID during the 48-month follow-up period (Trent et al., 2008). Although the CDC identifies adolescents as a special population in the STD Treatment Guidelines (Centers for Disease Control and Prevention, 2015), there are no longer special considerations for PID treatment among adolescents. Analyses of PEACH trial data led to the conclusion that inpatient treatment for mild to moderate PID would not be cost-effective for patients of any age. However, the PEACH trial had low representation among patients in early and middle adolescence: The mean age of participants younger than 19 years was 17.8 (SD = 1) years, which suggests that PEACH trial findings related to the effectiveness of outpatient treatment and self-management may not be applicable to younger adolescents (Trent, 2013a).

A quality improvement intervention for the outpatient management of PID in adolescents increased the proportion of emergency department (ED) and clinic patients who returned for follow-up care within 72 hours from 10% to 43%. However, patient adherence to care recommendations remained problematic. Fifty-seven percent of patients did not follow

up for care, and almost 40% of patients had not completed taking their medications at two weeks post-diagnosis. In structured follow-up telephone interviews, 47% of patients did not identify what prevented them from following up for care, and 20% could not provide a reason for their failure to complete the prescribed medication regimen (Trent, Judy, Ellen, & Walker, 2006). In a randomized controlled trial of a brief video behavioral intervention for adolescents with mild to moderate PID, only 24% of all patients returned for a 72-hour follow-up clinical visit, and almost one-third of all participants did not complete their medications, with no statistically significant differences between the intervention and control groups (Trent, Chung, Burke, Walker, & Ellen, 2010). Clinical quality improvement and behavioral interventions have generated limited improvements in outpatient PID treatment adherence, which suggests that factors beyond clinician practices, patient education, and behavioral modeling influence PID self-care. Psychosocial factors, such as coping strategies and social support, may influence self-care behaviors among young women diagnosed with PID, and therefore warrant exploration.

Coping and Social Support

The illness experience, receiving an illness diagnosis, and receiving medical treatment all may provoke reactions of stress in individuals. The ways that individuals experience and cope with stress influence whether and how they seek health care and social support, as well as their adherence to health care professionals' recommendations (Glanz, Rimer, & Viswanath, 2008). Reactions to stressors can promote or inhibit positive health behaviors and influence motivation to practice health-promoting behaviors. A better understanding of coping strategies, responses, and resources is essential to developing

effective strategies and programs for individuals to improve coping and enhance well-being (Glanz et al., 2008).

Coping is defined as cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person (i.e., coping is the effort to manage psychological stress) (Glanz et al., 2008). Multiple approaches have been used to classify coping, including an emphasis on the focus of coping (i.e., a person's orientation and activity in response to a stressor) or an emphasis on the method of coping (i.e., cognitive or behavioral efforts). Regarding the focus of coping, a person may approach the problem and make active efforts to resolve it (problem-focused coping) or try to avoid the problem and focus on managing the emotions associated with it (emotion-focused coping) (Zeidner & Endler, 1996). In general, problem-focused forms of coping are more likely when persons appraise conditions as amenable to change. Emotion-focused forms of coping are more likely to occur in response to an appraisal that nothing can be done to modify harmful, threatening, or challenging environmental conditions (Lazarus & Folkman, 1984). Adequate coping allows for the achievement of goals (Perrez & Reicherts, 1992). Because coping is a process connected to context, the appropriateness or adequacy of a coping strategy is determined by its effects in a given situation and in the long term; no coping strategy is inherently maladaptive or adaptive (Lazarus & Folkman, 1984; Zeidner & Endler, 1996). Central to the analysis of coping with stressors is the concept that a given event or situation is perceived in diverse ways by different people. Furthermore, these subjective perceptions, rather than the objective stressors, are the main determinants of effects on behaviors (Glanz et al., 2008). Subjective self-report is the primary source of coping data (Lazarus & Folkman, 1984).

Social support is a resource for coping efforts, and may exist in the following forms: emotional, tangible, and informational (Lazarus & Folkman, 1984). Social support may be conceptualized as (1) perceived social support, (2) supportive relationships, (3) supportive networks, and (4) received social support. Perceived social support refers to the general belief that others are available and desire to help if the individual needs aid. Supportive relationships are dyadic social bonds from which persons can obtain resources that may facilitate coping. Supportive networks are groups of supportive relationships. Received support is the help that an individual obtains from others during a challenging situation. These conceptualizations of social support are not mutually exclusive, and no single conceptualization is sufficient to lead to a satisfactory understanding of the role of social support in coping (Zeidner & Endler, 1996).

Background Literature

A preliminary analysis from Technology Enhanced Community Health Nursing (TECH-N), a randomized controlled trial (RCT) of an intervention designed to improve health outcomes among young women with PID, indicated that 65% of young women with PID notified a parent of their diagnosis, and 74% of the young women who notified their parents received support such as advice, comfort, and medication reminders. Young women who reported a greater sense of responsibility for the well-being of others were less likely to notify a parent of their PID diagnosis. Young women who reported a greater sense that they could rely on others, or a greater sense that others recognized their competence and personal qualities were more likely to notify a parent of their PID diagnosis (Munoz Buchanan et al., 2016). However, the influence of that social support on PID self-care behaviors was not

examined. Increased understanding of PID self-care processes contextualized by coping and social support will allow clinicians to refine interventions to improve PID self-care.

Although there is a paucity of research on coping strategies and social support associated with PID, there have been some investigations of coping strategies and social support within the context of self-care for other STIs and HIV. Young women use multiple coping strategies in response to an STI diagnosis. A cohort of 177 adolescent females with a history of at least one STI episode used a mean of 7.5 strategies to cope with their most recent STI diagnosis, with no differences by age or number of previous STI episodes. Wishful thinking (95%), problem solving (81%), and emotional regulation (79%) were the most frequently used coping strategies (Rosenthal, Biro, Cohen, Succop, & Stanberry, 1995). An extension of that research on adolescent females' coping strategies in response to STI acquisition suggested that there are some differences in coping strategies used for an STI acquisition and coping strategies used for other interpersonal life stressors (e.g., stressor associated with a friendship). Problem solving was used less often in response to STI acquisition, and self-blame was used more often in response to STI acquisition (Baker et al., 2001). Among 259 men and women between the ages of 18 and 56 years who received a diagnosis of GC or CT at STI treatment centers, problem-focused coping was significantly associated with consistent condom use one month after STI diagnosis. Persons who reported sexual activity with one-time partners or had more than one regular partner were more likely to use denial as a coping strategy. Partner notification was not associated with any of the coping strategies assessed one month after STI diagnosis (Schwartz et al., 2008).

HIV-related research suggests that relationships between coping strategies and medication adherence. There is evidence that proactive coping strategies, turning to family,

spiritual coping, professional help, and physical diversions moderate the relationship between stigma and antiretroviral medication adherence among adolescent and young adult females living with HIV. At low usage of these coping responses, stigma was negatively associated with medication adherence. With high usage of these coping responses, stigma was no longer associated with medication adherence (Martinez et al., 2012).

Social support has been positively associated with HIV medication adherence (Edwards, 2006; J. D. Kelly, Hartman, Graham, Kallen, & Giordano, 2014; Scheurer, Choudhry, Swanton, Matlin, & Shrank, 2012), medical appointment attendance by people living with HIV (Bodenlos et al., 2007), STI-related care seeking (Fortenberry & Zimet, 1999), and protective sexual behaviors, such as consistent condom use and secondary abstinence (Crosby et al., 2001; Crosby, DiClemente, Wingood, & Harrington, 2002; Mazzaferro et al., 2006). Women living with HIV revealed in qualitative interviews that emotional and instrumental forms of social support from family members helped them adhere to their HIV medication regimens (Edwards, 2006). High social support predicted high antiretroviral therapy (ART) medication adherence among persons 18 years of age and older with a new diagnosis of HIV. Baseline tangible support scores were higher in persons who subsequently had at least 95% adherence to ART. In multivariate logistic regression, high overall social support (adjusted odds ratio [AOR] = 2.36, $p = 0.05$) and high tangible social support (AOR 3.01, $p = 0.02$) predicted ART adherence equal to or greater than 95%. (J. D. Kelly et al., 2014). A systematic review to evaluate the association between social support and medication adherence indicated that social support was positively associated with medication adherence and fewer missed doses among persons with HIV (Scheurer et al., 2012). Larger social support networks were significantly associated with higher levels of

health care appointment attendance among persons with HIV (Bodenlos et al., 2007).

Evidence suggests that most adolescents who seek STI-related care receive social support from parents and other family members, commonly in the form of informational support and companionship. The process of STI-related care-seeking often involves an adolescent's social network, which provides a variety of coping resources that may make care-seeking easier (Fortenberry & Zimet, 1999).

Compared to young women with high perceived social support, young women with low perceived social support were less likely to report consistent condom use (AOR = 0.28; 95% CI: 0.14-0.57). Young women with low perceived social support were more likely to have a history of STI (AOR = 2.05; 95% CI: 1.13-3.71) (Mazzaferro et al., 2006). A supportive family may provide an environment that protects female adolescents from engaging in STI risk behaviors such as not using condoms. Adolescent females who did not reside in a supportive family were approximately twice as likely to report not using a condom during their most recent episode of penile-vaginal sex with a steady partner. Adolescents not residing in a supportive family were 2.8 times more likely to report that they had not used condoms for penile-vaginal sex in the past 30 days. Female adolescents who did not reside in a supportive family were approximately twice as likely to report fear of condom negotiation, low self-efficacy for condom negotiation, and high perceived partner-related barriers to engaging in safer sex (Crosby et al., 2002). Living with the mother in a supportive family may provide an environment that promotes protective sexual behaviors for sexually active female adolescents. After controlling for parental monitoring, parent-adolescent communication about sexuality, and age, adolescents residing with their mothers in a perceived supportive family were approximately 50% less likely to report having unprotected

sex with any partner in the past 30 days, and approximately 50% less likely to report having sex with a non-steady partner in the past 6 months (Crosby et al., 2001).

Significance of the Study

PID during adolescence and young adulthood increases vulnerability to long-term adverse reproductive health outcomes and negative health-related quality of life, including the challenges of chronic pelvic pain and infertility (Brunham et al., 2015; Greydanus & Dodich, 2015). The national focus on infertility prevention is indicated by the Healthy People 2020 objective to reduce the proportion of reproductive aged women with impaired fertility (U.S. Department of Health and Human Services, 2018). The current study investigated factors associated with adherence to PID treatment recommendations among adolescents and young adult women and explored the context of PID self-care behavior. Previous studies of PID self-care behaviors have been limited to correlations with demographic characteristics such as age. Furthermore, prior research has not investigated the psychosocial barriers to and facilitators of PID self-care, nor explored the context of PID self-care behaviors. Because individuals' subjective interpretations of health threats significantly influence their emotional and health behavior responses (Glanz et al., 2008), it is important to assess young women's appraisals of PID. In this study, quantitative and qualitative data were collected and analyzed to identify factors that promote or hinder PID self-care among young women and to discover opportunities to improve adherence to PID treatment recommendations. In-depth interviews with adolescents and young adult women diagnosed with and treated for PID elucidated their appraisals of the diagnosis and their subsequent self-care processes. Results from surveys of attitudes, beliefs, and behaviors were merged with findings from in-depth interviews to enhance contextual understanding of PID self-care. While published qualitative research on

PID has reported on the experiences of women 18 years of age and older, this study adds to existing knowledge by exploring the experiences of adolescents as young as 14 years old.

Study Purpose

The purpose of this dissertation study was to investigate the coping strategies, social support, and self-care behaviors of young women recently diagnosed with PID. Utilizing a convergent mixed methods design approach, this study examined and explored the psychosocial factors that influence adherence to PID self-management recommendations among young women. Enhanced understanding of the context of health behaviors by young women diagnosed with and treated for PID may inform clinical interventions that promote wellness and prevent future STIs and PID.

Specific Aims and Associated Hypotheses

A combination of quantitative and qualitative research methods examined barriers to and facilitators of PID self-care, while providing detailed, contextual information to achieve the following specific aims:

Aim 1: To determine the coping strategies and types of social support utilized by young women diagnosed with PID.

Aim 2: To examine the relationships among coping strategies, social support, and engagement in PID self-care behaviors among young women.

Hypothesis 2.1: Young women who report greater use of problem-focused coping strategies (e.g., active coping, planning) will be more likely to engage in PID self-care behaviors.

Hypothesis 2.2: Young women who report higher levels of social support will be more likely to engage in PID self-care behaviors.

Hypothesis 2.3: Social support will moderate the relationship between coping strategies and engagement in PID self-care behaviors.

Aim 3: To explore the experiences of young women diagnosed with PID.

Conceptual Framework

The Transactional Model of Stress and Coping (TMSC), a framework for evaluating processes of coping with stressful events, was used to develop the aims of this study. Developed by Lazarus and Cohen, the TMSC posits that stressful experiences are construed as person-environment transactions, in which the impact of an external stressor or demand is mediated by the person's appraisal of the stressor (primary appraisal) and the psychological, social, and cultural resources at the person's disposal (secondary appraisal). Coping strategies that are employed to achieve problem management and emotional regulation generate outcomes of the coping process (e.g., psychological well-being, health behaviors such as treatment adherence). Primary appraisal is an individual's belief about the significance of an event as positive, challenging, irrelevant, benign, controllable, or stressful. Individuals initially tend to evaluate health problems as threatening or as negative stressors. Perceptions of susceptibility to the threat and perceptions of severity of the threat are two basic primary appraisals. Secondary appraisals include the perceived ability to change the situation, perceived ability to manage one's emotional reactions to the threat, and expectations about the effectiveness of one's coping resources. Coping strategies mediate the emotional and functional effects of primary and secondary appraisals. Coping outcomes are a person's adaptation to a stressor, after appraising the situation and resources and being influenced by coping efforts (Glanz et al., 2008).

The TMSC was selected for the current study because it is an interpersonal model of health behavior. Self-management of PID is an interpersonal process, as it requires the adoption of protective sexual behaviors to prevent STI reinfection and may involve other persons for care and support. The PID self-management behaviors of interest include clinical follow-up visit attendance, medication adherence, partner notification, and sexual abstinence during the treatment period, all collected via self-report. The Brief COPE instrument was used to measure coping, the Social Provisions Scale instrument was used to measure perceived social support, and questions regarding the supportive care provided by parents/guardians were used to measure received social support. The TMSC adapted for the current study is shown in Figure 1.1. The quantitative research methodology of the current study examined coping strategies in response to PID and the influence of social support on PID self-care, while the qualitative research methodology used in-depth interviews to explore the processes of PID self-care after primary and secondary appraisals of PID.

Dissertation Organization

This dissertation consists of six chapters. Chapter One provides an overview of the study, with attention to the purpose and aims of the dissertation, review of relevant background literature, the significance of the study, and the conceptual framework which guided the study.

Chapter Two (Manuscript One) provides a comprehensive review of the published literature on coping strategies and social support experienced by adolescents and young adults diagnosed with PID. This manuscript has been submitted to *Women & Health* for review.

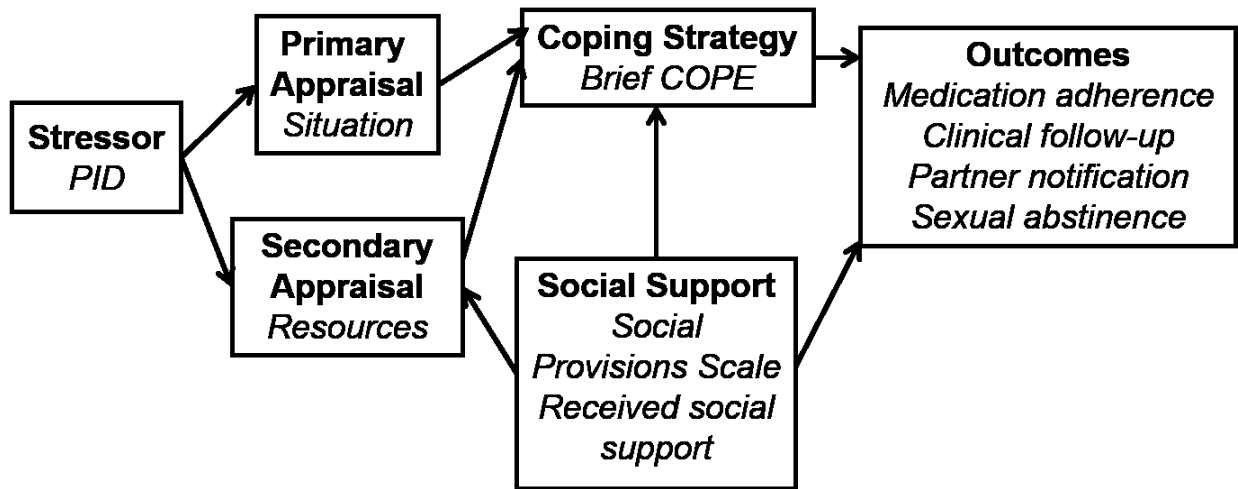
Chapter Three describes the methodology used to conduct this research, including the study design, description of the parent study, study setting and sample, data collection procedures, data analysis plan, and protection of human subjects.

Chapter Four (Manuscript Two) identifies social support and coping strategies utilized by 90 young women during the PID treatment period and examines their associations with the PID self-management behaviors of medication adherence, clinical follow-up visit attendance, partner notification, and sexual abstinence. This manuscript will be submitted to the *Journal of Pediatric & Adolescent Gynecology* for review. Included as an addendum to Chapter Four are tables that present the internal consistency reliabilities of the study instruments, the Social Provisions Scale and the Brief COPE.

Chapter Five (Manuscript Three) reports major findings from the quantitative and qualitative exploration of coping with PID self-management among 18 young women diagnosed with mild to moderate PID. Descriptive statistics were used to analyze perceived social support, coping strategies, social support received from parents/guardians, and PID self-management behaviors. Semi-structured interviews were conducted to explore the experiences of young women diagnosed with and treated for PID. This manuscript will be submitted to *Research in Nursing and Health* for review. Included as an addendum to Chapter Five is the abstract for a qualitative exploration of PID diagnosis disclosure among young women, which was presented as a poster at the 2018 Annual Meeting of the Society for Adolescent Health and Medicine. The abstract was published in 2018, and the citation is as follows: Tillman, J. L., Robinson, K., Sharps, P., Wenzel, J., Alexander, K., & Trent, M. (2018). "My body, my business" – Diagnosis disclosure in the context of pelvic inflammatory disease self-management. *Journal of Adolescent Health, 62*(3), S81.

Chapter Six presents a concise summary of the dissertation and integration of findings. It concludes with a discussion of the contributions of this research to young women's sexual and reproductive health and the implications of this research.

Figure 1.1 Adapted Transactional Model of Stress and Coping



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CHAPTER TWO: MANUSCRIPT ONE

Coping and Social Support among Adolescents and Young Adult Women Diagnosed with Pelvic Inflammatory Disease

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Abstract

Psychosocial factors such as coping and social support may influence the health behaviors of adolescents and young adult women with pelvic inflammatory disease. The purpose of this review was to examine published research on coping strategies and social support experienced by adolescents and young adults diagnosed with pelvic inflammatory disease. PubMed, PsycINFO, Web of Science, Embase, and CINAHL were searched for English language articles published through February 2017, using search terms including “pelvic inflammatory disease,” “coping,” “social support,” “Pelvic Inflammatory Disease/psychology,” and “Adaptation/Psychological.” Manual searches of article reference lists and database searches for publications that cited previously identified articles were conducted to identify additional relevant articles. The search identified 54 articles, and two articles met the inclusion criteria. Acceptance was identified as a coping response to pelvic inflammatory disease in one study, and a second study indicated that perceived social support is associated with voluntary parental notification of the diagnosis and parental engagement in care. Research designed to identify effective coping strategies and social support in diverse populations and settings is needed to inform the development of successful interventions that preserve reproductive health and improve health-related quality of life of adolescents and young adults diagnosed with pelvic inflammatory disease.

Keywords: Adolescent, coping, pelvic inflammatory disease, reproductive health, social support, women, young adult

Introduction

Pelvic inflammatory disease (PID) comprises a spectrum of inflammatory disorders of the female upper genital tract, including salpingitis, endometritis, tubo-ovarian abscess, and pelvic peritonitis (Centers for Disease Control and Prevention, 2015b; Handsfield, 2011). An estimated 600,000 to 1 million PID cases are diagnosed in the United States each year (Handsfield, 2011). Arising from an ascending genital infection unrelated to childbirth or invasive procedures of the genital tract, PID is the most common complication of sexually transmitted infections (STIs) (Handsfield, 2011). At least 90% of primary episodes of PID are sexually acquired and attributed to sexually transmitted organisms, such as *Neisseria gonorrhoeae* (GC) and *Chlamydia trachomatis* (CT) (Centers for Disease Control and Prevention, 2015b; Handsfield, 2011).

Estimates derived from Centers for Disease Control and Prevention (CDC) reports suggest that at least 20% of PID cases in the United States occur in adolescents (≤ 19 years old) (Greydanus & Dodich, 2015). Adolescents have a greater risk for subsequent STIs and PID, and adverse reproductive health outcomes than older women (Kelly, Ireland, & Aughey, 2004; Trent, Chung, Forrest, & Ellen, 2008; Trent, Haggerty et al., 2011; Trent, 2013). PID poses a long-term threat to reproductive health, with complications that include chronic pelvic pain, ectopic pregnancy, and tubal infertility (Brunham, Gottlieb, & Paavonen, 2015; Greydanus & Dodich, 2015; Westrom, 1975). The most recent estimate indicates that total direct medical costs for PID and PID sequelae in the United States reach \$1.88 billion per year (Rein, Kassler, Irwin, & Rabiee, 2000). Health economics studies have demonstrated that adolescents and adult women in the general population (i.e., with or without a history of PID) are willing to give up one to two years of life in perfect health to avoid the burden of

outpatient or inpatient PID treatment (Smith, Tsevat, Ness, Wiesenfeld, & Roberts, 2008; Trent, Lehmann et al., 2011). Effective treatment and prevention of recurrences are critical for the preservation of fertility and health-related quality of life among adolescent and young adult (AYA) women diagnosed with PID.

PID symptoms include lower abdominal pain, abnormal vaginal discharge, dyspareunia, and non-menstrual vaginal bleeding, although research suggests that subclinical or asymptomatic PID cases are common (Wiesenfeld et al., 2002). Severe PID cases include complicating symptoms, such as nausea and vomiting, which require hospital admission for treatment (Handsfield, 2011). The current Centers for Disease Control and Prevention (CDC) standard of care treatment guidelines for mild to moderate PID in non-pregnant women includes a 14-day course of outpatient oral antibiotic therapy and pain management, partner notification for treatment, sexual abstinence until patient and partner are treated, and a follow-up clinical evaluation by a medical or nursing professional within 72 hours of diagnosis and initiation of therapy (Centers for Disease Control and Prevention, 2015b). Although PID in pregnancy is rare, pregnant women diagnosed with PID should be hospitalized and treated with intravenous antibiotics due to their risk for complications such as preterm delivery (Centers for Disease Control and Prevention, 2015b). The current PID treatment guidelines from the CDC were influenced by the results of the PID Evaluation and Clinical Health (PEACH) study, a large, multisite randomized clinical trial to compare the effectiveness of inpatient and outpatient therapies. While the study confirmed prior reports of adverse outcomes in both treatment groups, there were no significant differences observed in the outcomes associated with short-term inpatient hospitalization to bolster antibiotic

treatment versus outpatient self-management of antibiotic therapy (Ness et al., 2002; Ness et al., 2005).

Many AYA diagnosed with PID fail to fully adhere to the CDC-recommended treatment for PID (Dunbar-Jacob, Sereika, Foley, Bass, & Ness, 2004; Kelly et al., 2004; Trent et al., 2008; Trent et al., 2011). For example, in a subsample of PEACH study participants, medication adherence measured by electronic event monitoring demonstrated that participants took an average of 70% of prescribed doses of doxycycline and took the prescribed two daily doses for less than 50% of outpatient treatment days (Dunbar-Jacob et al., 2004). Failure to complete the antibiotic treatment regimen for PID increases susceptibility to persistent infection and ongoing inflammation, which may lead to PID sequelae (Rosenberg & Waugh, 1995).

Multiple intervention strategies have been tested to improve adherence to PID treatment recommendations. A quality improvement intervention for the outpatient management of PID in AYA increased the proportion of emergency department (ED) and clinic patients who returned for follow-up care within 72 hours from 10% to 43%. However, the intervention was not successful in improving patient adherence. Fifty-seven percent of patients did not follow up for the recommended 72-hour follow-up care, and almost 40% of patients did not complete the course of prescribed medications (Trent, Judy, Ellen, & Walker, 2006). In a randomized controlled trial of a brief educational video designed to improve PID self-management among adolescents diagnosed with mild to moderate PID, the odds of returning for a 72-hour follow-up medical visit were 2.65 times higher among adolescents who were randomized to the video intervention (Trent, Chung, Burke, Walker, & Ellen, 2010). However, the proportion of intervention group participants that returned for the 72-

hour follow-up visit was only 32%, and almost one-third of participants in the intervention and control groups did not complete their medications (Trent et al., 2010). The limited improvements in outpatient treatment adherence generated by clinical quality improvement and behavioral interventions suggest that factors beyond clinician practices and patient education influence PID self-care among AYA. Psychosocial factors such as personal coping strategies and social support may significantly influence self-care behaviors among AYA diagnosed with PID.

The illness experience, receiving an illness diagnosis, receiving medical treatment, and medical self-management all may provoke reactions of stress in individuals (Glanz, Rimer, & Viswanath, 2008). The ways that individuals experience and cope with stress may influence whether and how they seek health care and social support, as well as their adherence to health care professionals' recommended treatment protocols and follow-up visits. Reactions to stressors can promote or inhibit health behaviors and influence motivation to practice health-promoting behaviors (Glanz et al., 2008). Coping, defined as cognitive and behavioral efforts to manage specific external and/or internal demands appraised as taxing or exceeding the resources of the person, is the attempt to manage psychological stress (Glanz et al., 2008). Social support, or help obtained from others, is a resource for coping and commonly indicated as an important strategy on many coping instruments (Carver, Scheier, & Weintraub, 1989; Carver, 1997; Glanz et al., 2008; Spirito, Stark, & Williams, 1988).

During adolescence and emerging adulthood, individuals move toward independence and autonomy, and the composition and dynamics of their social networks change. The peer group increases in importance, and dependence upon parents decreases in preparation for

adulthood. However, the family remains a critical source of support (Muuss, Velder, & Porton, 1996). AYA receive social support and other coping resources from parents, peers, and other social network members, and social support has been positively associated with well-being (Chu, Saucier, & Hafner, 2010). Physicians and nurses are a critical part of the support safety net for AYA who manage their own health care without the benefit of a personal social network. For interdisciplinary health care providers to develop and implement effective strategies to improve AYA health outcomes after PID, it is important to understand how AYA cope with a PID diagnosis and the role of social support in PID self-care outside the hospital setting. The objective of this paper is to examine the status of research focused on coping strategies and social support among AYA with PID.

Methods

Data Sources

A comprehensive review of the literature was conducted to identify studies related to coping and/or social support among adolescents and young women diagnosed with PID. The literature review comprised peer-reviewed journal articles published in the English language. Five electronic databases—PubMed, PsycINFO, Web of Science, Embase, and CINAHL—were searched for all articles published through February 2017. To maximize the retrieval of relevant articles, we did not apply publication date limits to our search. Search terms included “coping,” “social support,” “pelvic inflammatory disease,” and specific PID disorders such as “endometritis” and “salpingitis.” In databases that used Medical Subject Headings (MeSH) terms, literature searches included MeSH terms such as “Pelvic Inflammatory Disease/psychology” and “Adaptation/Psychological.” Manual searches of article reference lists and database searches for publications that cited the previously

identified articles also were conducted to identify additional relevant articles and ensure a sufficiently exhaustive search.

Study Selection

Articles were included for review if they presented original research on coping strategies by AYA in response to the stressors of receiving a PID diagnosis and PID treatment, or social support related to receiving a PID diagnosis and PID treatment. For this review, AYA is defined as the age range of 15 to 24 years, consistent with the “adolescents and young adults” population identified by the CDC (Centers for Disease Control and Prevention, 2015a). Articles were excluded from review if the study sample included AYA without a clear history of PID, and/or the results were not stratified by diagnosis to permit separate analysis of AYA who had been diagnosed with PID. Rigid quality assessment criteria were not used to further exclude studies, due to the paucity of studies focused on coping or social support identified in the literature. A single reviewer performed the literature search and compiled search results according to selection criteria, and two additional reviewers assessed the identified articles for inclusion in the manuscript.

Analysis

For each included study, data were extracted on study type, setting and population, number of participants, study aims, the methods and instrument(s) used, and the results reported. Given the varied nature of the studies included in this paper, the data could not be combined in a meta-analysis. The studies are reviewed individually, and their applicability to the examination of coping and social support among AYA with PID is presented in the manuscript.

Results

The search for published literature yielded 84 initial results, published between 1978 and 2016. Search results were imported into the Refworks reference manager program and checked for duplicates. Fifty-four papers remained after duplicates were removed. Each title was screened for inclusion/exclusion criteria, and potentially relevant papers were further assessed by abstract review. Forty-three papers were excluded after title/abstract screening based upon the following criteria: If the title and abstract had nothing to do with PID, then the study was excluded as off-topic. If the title and abstract did not pertain to social support or coping strategies after PID diagnosis, then the study was excluded. Of the eleven remaining results, nine did not meet the inclusion criteria for the following reasons: (1) lack of description of coping or social support after a PID diagnosis ($n = 5$); (2) editorial or opinion paper lacking original research ($n = 2$); or (3) inclusion of study participants with and without a history PID, without results stratified by PID history and AYA age ($n = 2$). Two full-text articles met the inclusion criteria for this review. A PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram in Figure 2.1 shows the steps taken and the number of references included and excluded at each stage (Moher, Liberati, Tetzlaff, Altman, & PRISMA Group, 2009).

Coping with PID

Our search yielded no studies with a specific objective to examine coping with a PID diagnosis among AYA, or women of any age. However, a cursory recount of coping occurred in one qualitative study that investigated women's health care experiences and the impact of the PID diagnosis on their feelings about their health. Newton et al. (2014) conducted semi-structured telephone interviews with 23 women 18 to 46 years old in

Melbourne, Australia who were diagnosed with PID at a metropolitan sexual health clinic, metropolitan public hospital, or general practice office. The effect of the PID diagnosis on the women's feelings about their health was one theme derived from the interviews. Some women conveyed that finding out about their PID diagnosis increased their body awareness and made them more likely to pay attention to symptoms in the future. However, there was no specific discussion regarding how the women managed their diagnosis and adhered to treatment recommendations (i.e., took care of themselves to cure PID and prevent future recurrences). A few women (n = 8) expressed the shock of discovering something was wrong with their normally healthy body and discussed how the PID diagnosis generated anxiety about their overall health. One coping strategy described by the participants was acceptance, which reflected their attempts to adjust to a perceived future of infertility. Most women in the study had been diagnosed with PID relatively recently (i.e., less than four months prior to study participation), thereby reducing the risk for recall loss as they recounted their experiences.

Social Support for AYA with PID

Social support within the context of a PID diagnosis was studied in a sample of 187 young women 14-25 years old (mean 18.4 years [SD = 2.2]) participating in a randomized control trial designed to evaluate a community health nursing intervention supplemented by text message communication to reduce short-term adverse health outcomes among young women diagnosed with PID (Munoz Buchanan et al., 2016). The purpose of the study was to examine factors associated with parental notification initiated by young women diagnosed with PID and subsequent parental involvement in the young women's PID care. Parental notification—dichotomized as a “yes” or “no” response to the question “Did you notify your

parent or legal guardian about your PID diagnosis?”—was the primary outcome of the study. Perceived social support (i.e., the belief that others are available and desire to help if the individual needs it) was operationalized as the Social Provisions Scale (SPS), a 24-item instrument that measures social support in six domains: attachment (emotional closeness that provides a sense of security), social integration (a sense of belonging to a group with similar interests and concerns), reassurance of worth (acknowledgment of one’s competence, skills, and value), reliable alliance (assurance that others can be counted on for tangible aid), guidance (advice and information), and opportunity for nurturance (the sense that others depend upon oneself for their well-being) (Cutrona & Russell, 1987). The SPS includes four items for each of the six domains, which are scored on a four-point scale (1 = “strongly disagree” to 4 = “strongly agree”). Higher scores indicate a greater level of perceived social support. Received social support (i.e., help obtained from others) examined in this study was parental engagement in PID care, which included the provision of medication reminders, advice, or comfort. Parental engagement in PID with care was reported in aggregate, and not itemized by specific support activity.

Among the AYA diagnosed with PID in the Munõz Buchanan et al. (2016) study, 65% (n = 121) of participants notified a parent of their PID diagnosis, with a significantly higher parental notification rate among adolescents (14-17 years old) than young adults (18-25 years old) (85.9% vs. 53.7%, $p < 0.001$). Among participants who notified a parent of their PID diagnosis, 74% reported parental engagement in their PID care. There was no statistically significant difference in parental notification between intervention and control group participants. Controlling for age and intervention group assignment, the Opportunity for Nurturance, Reassurance of Worth, and Reliable Alliance subscales were significantly

associated with parental notification. Participants who reported a greater sense of responsibility for the well-being of others (Opportunity for Nurturance subscale) were 17% less likely to notify a parent about their diagnosis (adjusted odds ratio [AOR] = 0.829 [95% CI: 0.707, 0.973]; $p = 0.022$). Participants who reported a greater sense that others recognized their competence, skills, and value (Reassurance of Worth subscale) were 20% more likely to inform a parent about their diagnosis (AOR = 1.197 [95% CI: 1.008, 1.422]; $p = 0.040$). Participants who reported a greater level of assurance that they could count on others for help (Reliable Alliance subscale) were 16% more likely to notify a parent about their PID diagnosis (AOR = 1.160 [95% CI: 1.023, 1.317]; $p = 0.021$). The presence or absence of statistically significant associations between perceived social support (SPS subscales) and received social support (parental engagement in PID self-care activities) were not reported. Further, the authors did not report the frequency of each supportive activity provided by parents and whether parental notification and/or parental engagement in self-care were associated with increased participant adherence to PID treatment.

Discussion

The findings from this review of literature indicate that few studies have examined how young women cope with a PID diagnosis, or the role of social support after receiving a PID diagnosis. Only two published studies were relevant to the topics of interest. In the one paper that minimally covered coping with PID, the only coping strategy described was acceptance. However, acceptance pertained to expectations of the long-term sequela of infertility, not to the immediate PID diagnosis and treatment period. No studies specifically examined the coping strategies used by AYA diagnosed with and treated for PID. Further, there was no published research with a stated aim or objective to examine coping with PID

among girls or women of any age. As such, there were no identified studies that used coping-specific questions and/or validated instruments to evaluate coping with PID.

While no published research has measured coping with PID, a few studies have examined AYA coping with related STIs (e.g., gonorrhea and chlamydia). The KIDCOPE, a 10-item standardized instrument developed to assess coping with various kinds of problems, has been used to evaluate the coping strategies of adolescent girls in response to STI acquisition (Baker et al., 2001; Rosenthal, Biro, Cohen, Succop, & Stanberry, 1995). Each KIDCOPE item represented a different form of coping: blaming others, cognitive restructuring, distraction, emotional regulation, problem solving, resignation, self-criticism, social support, social withdrawal, and wishful thinking. Using a 4-point scale from 1 = “not at all” to 4 = “almost all the time,” study participants indicated how frequently they used each strategy. They utilized a 5-point scale ranging from 1 = “not at all” to 5 = “very much” to rate the helpfulness of the coping strategies they employed (Baker et al., 2001; Rosenthal et al., 1995). In a study of 177 adolescent girls (mean age = 16.8 years) with a history of at least one STI episode, the adolescents used a mean of 7.5 coping strategies. Wishful thinking was the most frequently reported coping strategy (95%), followed by problem solving (81%) and emotional regulation (79%). However, unlike problem solving and emotional regulation, frequency of wishful thinking use was not correlated with perceived helpfulness. Reasons for adolescents using a coping strategy they believed was unhelpful were not determined (Rosenthal et al., 1995).

To extend Rosenthal and colleagues’ (1995) research on coping with STIs among adolescent girls, Baker et al. (2001) utilized the KIDCOPE to evaluate whether adolescent girls use similar coping strategies in response to STI acquisition and other life stressors. The

selected “other life stressor” was a moment during the previous six months when the adolescent was upset because of a friend. Wishful thinking (96%), blaming others (78%), and internal emotional regulation (72%) were the most frequently used coping strategies in response to STI acquisition. Self-blame was used more often in response to STI acquisition than in response to the interpersonal stressor (40% vs. 26%, $p < 0.01$), while problem solving was used less often (43% vs. 58%, $p = 0.03$). In response to STI acquisition, problem solving was positively correlated with perceived helpfulness ($r = 0.73$, $p < 0.01$), but the frequency of self-blame use was not correlated with perceived helpfulness ($r = 0.01$, $p = 0.93$). While study findings indicated that adolescent girls used some coping strategies differentially in response to STI acquisition compared to an interpersonal stressor, the sample size was too small ($n = 67$) to determine whether coping strategies varied by STI pathogen or STI history, or whether coping strategies were associated with future sexual health-related behaviors.

Regarding social support for AYA diagnosed with PID, results from Muñoz Buchanan et al. (2016) indicated that most young women with PID inform a parent of their diagnosis and receive supportive care from a parent. Believing that one could count on others for help and sensing that others recognized one’s competence were positively associated with parental notification of the PID diagnosis. Perceiving an increased sense of responsibility for the well-being of others was negatively associated with parental notification. To tailor the plan of care for a young woman diagnosed with PID, nurses and physicians should inquire about her access to supportive care and whether she is a parent or caregiver herself, since young women with a greater sense of responsibility for others were less likely to notify a parent of their diagnosis (and therefore more likely to manage PID self-care on their own) (Munoz Buchanan et al., 2016). This study suggests that parents are an important source of

help for AYA receiving outpatient PID treatment and emphasizes the value of positive relationships with parents or other adults among AYA diagnosed with PID. While there is only one published study of social support for AYA diagnosed with PID, other studies have examined relationships between social support and STIs in AYA. However, the research related to social support and STIs among adolescents and young adults has pertained to seeking STI-related health care (Fortenberry & Zimet, 1999; Lowery, Chung, & Ellen, 2005), engaging in STI risk behaviors (Crosby et al., 2001; Crosby, DiClemente, Wingood, & Harrington, 2002; Mazzaferro et al., 2006), or self-reported STI history (Gao & Chen, 2011), not social support received after STI diagnosis and/or related to STI treatment adherence.

While participants in all stages of adolescence were included in the study of perceived social support after receiving a PID diagnosis, the youngest participant in the study of perspectives on the impact of PID and coping strategies was 18 years old. Considering that at least 20 percent of PID cases in the United States occur in adolescents—who may not possess the developmental resources necessary to manage their self-care—and PID during adolescence increases vulnerability to long-term adverse reproductive health outcomes and negative health-related quality of life (Kelly et al., 2004; Trent et al., 2008; Trent et al., 2011; Trent, 2013), it is important to include younger adolescents in studies of psychosocial responses to PID.

The paucity of published research also limited the description and discussion of diverse experiences with PID. The two studies included in this review of published research were conducted in only two countries: Australia and the United States. Most women (15 of 23) in the Newton et al. (2014) qualitative study of women's health care experiences with PID were born in Australia, but no racial/ethnic information about them was provided. In

addition, the mean age of the study participants was more consistent with young adulthood than adolescence. The Munõz Buchanan et al. (2016) study of parental notification, perceived social support, and parental engagement in PID care among AYA was the only study conducted in the United States. The limited research conducted in the United States is problematic, considering the previously noted significant burden of PID among AYA in the United States. Regarding racial/ethnic representation in study participation, most (94%) participants in the Munõz Buchanan et al. (2016) study of perceived social support, parental notification, and parental engagement in the care of AYA diagnosed with PID were Black/African American. Participants in the large national randomized trial that guided the CDC guidelines on PID management (Ness et al., 2002) also were disproportionately Black/African American (i.e., 74.6% of outpatient treatment group and 74.8% of inpatient treatment group). Acknowledging that the lifetime self-reported history of PID diagnosis among non-Hispanic Black and non-Hispanic White sexually experienced women of reproductive age (18-44 years) in the United States with a previous STI diagnosis is nearly equal (10.0 % vs. 10.3%), it is important to include all groups affected by the disease (Kreisel, Torrone, Bernstein, Hong, & Gorwitz, 2017).

While this is the first review to examine the roles of coping and social support in AYA with PID, our findings must be considered with several general limitations, including generalizability of results. It is likely that the study participants do not represent all AYA diagnosed with and treated for PID. Most participants (87%) in the Newton et al. (2014) qualitative study of women's health care experiences with PID were recruited from one metropolitan sexual health clinic, whose patient population and health care delivery may differ from that of other health services providers. Participants in the Munõz Buchanan et al.

(2016) study of parental notification, perceived social support, and parental engagement in PID care among AYA comprised a highly racially and socioeconomically homogeneous group recruited from one academic health center located in a single city with high STI prevalence. The few published studies about coping strategies and social support specific to PID diagnosis and treatment limit the conclusions that this review may provide, but it also indicates the need for additional research to strengthen the evidence.

Clinical Implications

Treatment adherence is critical for preserving the health and quality of life of women diagnosed with PID. Evidence suggests that AYA women with PID often do not adhere to prescribed treatment guidelines, leaving them vulnerable to chronic pelvic pain, tubal infertility, ectopic pregnancy, and other adverse outcomes associated with unresolved or recurrent PID (Brunham et al., 2015; Greydanus & Dodich, 2015; Westrom, 1975). While quality improvement interventions that focus on clinician practices and theory-based interventions designed to change patients' behaviors have achieved modest success in increasing the rates of women with PID who complete their medication regimen or return for follow-up care, overall adherence to treatment recommendations remains low. Psychosocial factors such as coping strategies and social support may influence a woman's level of engagement in PID self-management. Evidence-based understanding of how AYA cope with a PID diagnosis and perceive and use available social support will inform the development of effective treatment and self-management plans tailored to the needs and available resources of the young women. The finding that young women who perceive a greater sense of responsibility for others are less likely to enlist the support of a parent to manage their PID diagnosis suggests that nurses and physicians should inquire about young women's support

resources and caregiver responsibilities when developing a plan of care. Through patient education and various forms of instrumental and emotional support, nurses have the capacity to provide strategies that enhance PID self-care and the prevention of PID recurrence and adverse reproductive health outcomes.

Future Directions of Research

The paucity of research on coping and social support associated with PID diagnosis and treatment provides limited evidence to inform clinical and community-based interventions to support the therapeutic trajectories of AYA diagnosed with PID. A limitation of the existing research is that it has focused on seeking and receiving care for PID, not subsequent self-care after PID diagnosis. Quantitative and qualitative studies conducted in diverse settings with diverse populations are needed to examine how adolescent and young adult women cope with PID to optimize treatment strategies and subsequent reproductive health outcomes. Current research suggests that AYA struggle with treatment adherence (Butz et al., 2016; Dunbar-Jacob et al., 2004) and have significant adverse reproductive outcomes associated with recurrent disease (Ness et al., 2002; Ness et al., 2005; Trent, Bass, Ness, & Haggerty, 2011; Trent et al., 2011). Structured questionnaires with validated instruments to measure coping are needed to identify the types of coping strategies used and factors associated with effective coping in PID-affected women, considering the negative impact on health-related quality of life associated with PID complications such as chronic pelvic pain (Haggerty, Schulz, & Ness, 2003). Questionnaires administered to larger and more diverse study populations in a variety of settings would provide robust evidence to inform intervention strategies. Detailed exploration of participants' experiences and

perspectives via additional qualitative studies would further contextualize coping with PID and adherence to PID treatment guidelines.

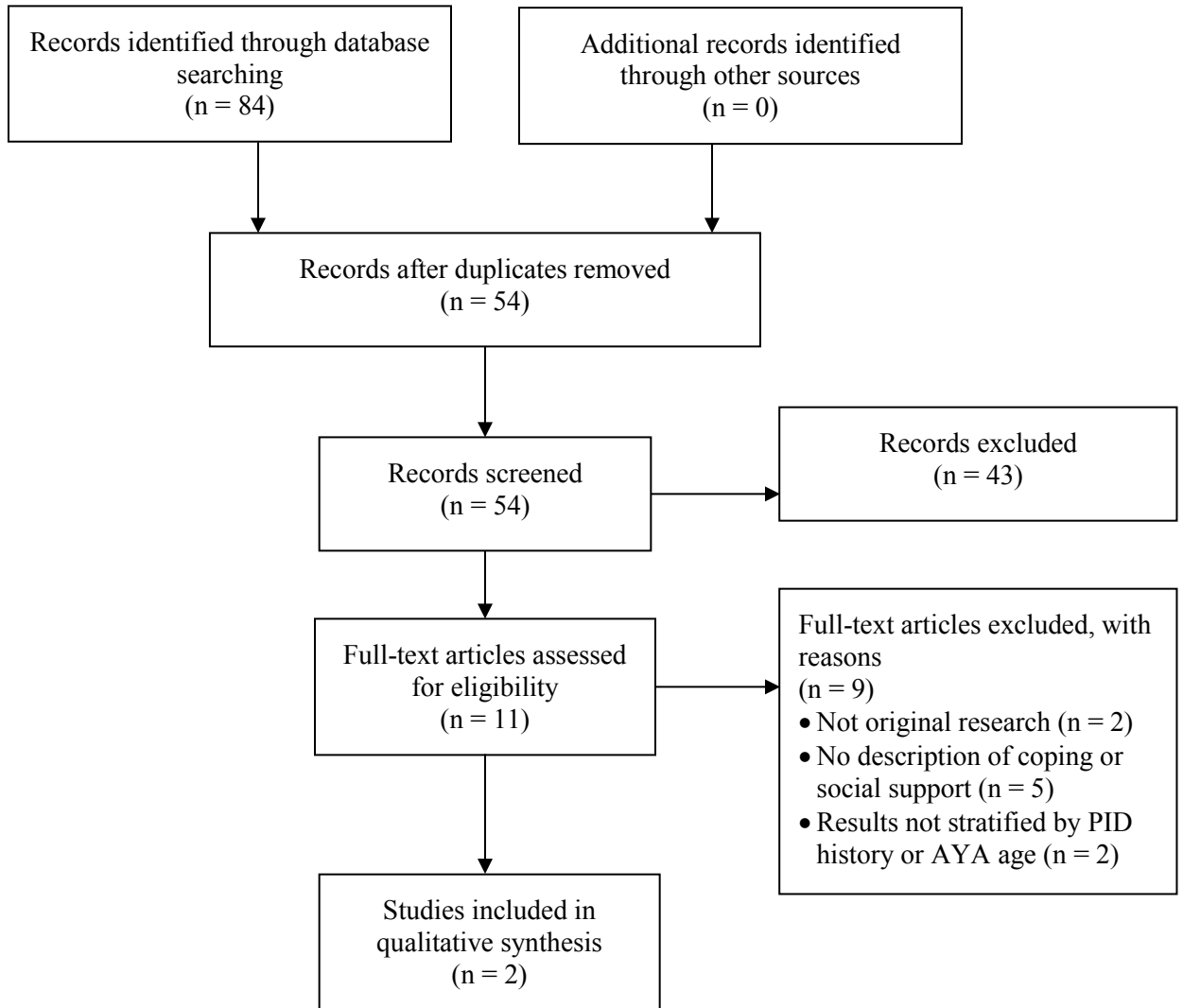
While Munõz Buchanan et al. (2016) determined that AYA who perceive that they can count on others for help or perceive that others recognize their competence are more likely to notify a parent about their PID diagnosis, and that most AYA who notified a parent about their PID diagnosis received supportive care from a parent, it is unclear whether perceived social support and parental engagement in care are associated with AYA adherence to PID treatment guidelines. Associations between perceived social support, specific supportive care received from parents, and adherence to the treatment regimen among AYA diagnosed with PID should be examined. Prior research has demonstrated the feasibility of a community-based nursing intervention to support AYA diagnosed with PID (Trent et al., 2016). Investigation of psychological responses to the PID diagnosis and the relationships among coping strategies, social support, and subsequent self-care is needed to identify priorities for nursing interventions to promote positive health outcomes among young women diagnosed with PID.

Conclusion

Published studies provide limited information regarding coping strategies and social support within the context of PID diagnosis and treatment among AYA women. The dearth of research focused on coping with PID and related social support among AYA women presents an opportunity to examine the person-centered influences on self-management. Understanding the coping strategies and social support utilized by AYA women diagnosed with PID will inform nursing, other clinical, and public health interventions designed to promote self-care and preserve reproductive health within this vulnerable population at risk

for recurrent STIs and PID (Kelly et al., 2004; Trent et al., 2008; Trent et al., 2011; Trent, 2013).

Figure 2.1 PRISMA Literature search flow diagram



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CHAPTER THREE: METHODOLOGY

This chapter describes the methodology of the current study, which employed a convergent mixed methods design to determine the influences of coping strategies and social support on PID self-care among young women. Quantitative and qualitative data were collected during the same period, each providing important insights pertaining to PID self-care. The quantitative and qualitative data sets were analyzed separately and independently and then merged to compare, contrast, and synthesize the results (Creswell & Plano Clark, 2011).

Description of Parent Study

Study data were collected from young women participating in Technology-Enhanced Community Health Nursing (TECH-N) (5R01NR013507, M. Trent, PI). As described in previously published research (Butz et al., 2016; Trent et al., 2016), TECH-N was a large RCT funded by the National Institute of Nursing Research (NINR) to evaluate an intervention consisting of daily medication reminders via text messaging and a follow-up clinical visit by a community health nurse (CHN) to improve clinical outcomes among young women diagnosed with mild to moderate PID. From September 2012 to December 2016, TECH-N study participants were recruited from the pediatric and adult emergency departments and a general pediatrics and adolescent medicine clinic at a large academic health center in Baltimore, Maryland. Patients enrolled in the study on the same day they were diagnosed with PID. Eligible participants were non-pregnant young women 13 to 25 years old residing in the Baltimore, Maryland metropolitan area, diagnosed with mild to moderate PID, and receiving outpatient PID treatment. Young women who were unable to

communicate in English or were admitted to the hospital to receive inpatient PID treatment were excluded from study participation.

At baseline, all participants were tested for STIs (GC, CT, *Mycoplasma genitalium*, and *Trichomonas vaginalis*) and provided demographic, behavioral (e.g., medication self-efficacy, sexual self-efficacy), social (e.g., perceived social support), and health history information via ACASI. Three to five days after study enrollment, participants in the intervention group met with the CHN at home or a mutually established location for a clinical assessment. All participants met with an outreach worker for follow-up study visits at 14, 30, and 90 days. At the 14-day visit, participants were queried via structured face-to-face interview about medication adherence, partner notification and treatment, temporary abstinence from sexual intercourse, and social support received from parents/guardians during the treatment period. At the 30- and 90-day visits, participants were tested for STIs and completed an ACASI focused on health behaviors and symptoms. TECH-N study outcomes of interest included medication adherence, adherence to the 3- to 5-day clinical follow-up visit, and STIs at 90 days. The Johns Hopkins Medicine institutional review board (IRB) approved the TECH-N study.

The current study used the TECH-N study population and data to investigate relationships among coping, social support, and PID self-management and to explore the experiences of young women diagnosed with and treated for PID. As indicated in Figure 3.1, data analyzed for this dissertation were collected from control and intervention group participants at the baseline, 14-day, and 30-day visits and from a subsample of control group participants who completed semi-structured interviews after the 90-day visit. Control group participants were interviewed to elucidate their experiences with PID standard of care

treatment. The current study did not assess the effects of the parent study intervention or the primary outcomes of the ongoing parent study. Additions made to TECH-N to conduct this study are outlined in blue in Figure 3.1 and described below. Approval from the Johns Hopkins Medicine IRB was obtained for the addition of the Brief COPE, an instrument to measure coping strategies, to the TECH-N 14-day visit protocol and for the conduct of semi-structured in-person interviews after completion of the TECH-N 90-day visit to explore young women's experiences with PID diagnosis and treatment. The current study includes participants who enrolled in the TECH-N study between June 2015 and December 2016, a period that commenced with the addition of the Brief COPE to the TECH-N protocol and concluded with the scheduled completion of TECH-N study enrollment.

Dissertation Study Design

Sampling and Sample Size

The study sample to achieve Aims 1 and 2 consisted of non-pregnant young women 13 to 25 years old residing in the Baltimore metropolitan area, diagnosed with mild to moderate PID, and receiving outpatient treatment for PID. Young women who were unable to communicate in English or were receiving inpatient PID treatment were excluded from study participation. The sample comprised a subgroup of TECH-N participants who completed the Brief COPE instrument at the 14-day visit interview. There were no additional exclusion criteria for the current study. The Brief COPE was added to the TECH-N protocol in June 2015. In consideration of TECH-N recruitment activity around that time, it was estimated that 100 participants would be enrolled in the study and complete the Brief COPE prior to TECH-N study completion. A priori power analyses were conducted for Aim 2 using an odds ratio (OR) from a previous study of perceived social support and sexual risk

behaviors among adolescent females, in which the odds of not using a condom during last sexual intercourse were 1.92 times greater among adolescent females who lacked social support (Crosby et al., 2002). The power calculations suggested that a sample size of 100 would have at least 80% power to detect an OR of 1.92 or more at $\alpha = 0.05$, using a binary logistic regression model. G*Power version 3.1.7 software was used for the power analysis (Faul, Erdfelder, Buchner, & Lang, 2009). Despite a continuous effort to reach 100, the final sample size for Aims 1 and 2 was 90 participants.

To achieve Aim 3, the sample consisted of young women 13 to 25 years of age who received standard of care treatment for mild to moderate PID, selected from the cohort of TECH-N control group participants who completed the 90-day protocol visit. Purposive sampling of control group participants was used to explore young women's experiences with PID that were not potentially influenced by the TECH-N intervention. Considering the limited research on young women's experiences with PID, the phenomenon of PID self-management among young women who received standard of care treatment may be of broader clinical interest than the enhanced experiences specific to the TECH-N intervention. The demographic characteristics of the qualitative interview sample were expected to be consistent with that of the parent study population: largely black/African American, non-Hispanic, low-income women. Due to the relative homogeneity of the sample in terms of race, ethnicity, and socioeconomic status, efforts were made to maximize variation by age group and explore the PID-related experiences among younger (adolescents aged 13-19 years) and older (young adults aged 20-25 years) participants. Adolescents diagnosed with PID are at increased risk for subsequent STIs (Trent et al., 2011), which suggests that adolescents' post-PID diagnosis experiences may be different from those of their young adult

counterparts. Participants were recruited until qualitative data saturation occurred; interview data were analyzed after each interview, and subsequent interviews were conducted and analyzed until no new themes emerged from the data. Qualitative data saturation was reached with 18 interviews, a sample size approximating previously published qualitative research on women diagnosed with PID (Newton et al., 2014).

Participant Recruitment and Enrollment

Study participant recruitment and enrollment for Aims 1-2 has been described in previously published manuscripts about the TECH-N parent study (Butz et al., 2016; Trent et al., 2016). For Aim 3, young women between the ages of 13 and 25 years, who were diagnosed with and treated for mild to moderate PID at the pediatric emergency department, adult emergency department, or pediatric and adolescent medicine clinic of Johns Hopkins Hospital within the five years preceding the study were eligible for study participation. Young women were recruited from the control group of TECH-N. The TECH-N study had IRB approval for continued participant contact beyond the initial 90 days, and IRB approval was obtained for the qualitative research phase of this study. Potential study participants were contacted after completion of the 90-day TECH-N protocol visit. Each participant provided written informed consent prior to the initiation of research study activities.

Data Collection

For Aims 1-2, demographic, behavioral, social (e.g., perceived social support), and health history information were collected during the baseline visit via ACASI. Follow-up data on self-care behaviors and received social support were collected via structured interview at the 14-day visit and ACASI at the 30-day visit. All participants were assigned a

study identification number; personally-identifiable information was removed to ensure confidentiality.

Using a qualitative descriptive approach (Sandelowski, 2000), data collection for Aim 3 consisted of one-time, in-person, semi-structured interviews, each approximately 30 minutes (mean = 31.6 minutes) in duration. Using open-ended questions developed with and organized by TMS constructs, interviews were conducted between January 2017 and April 2017 to explore the experiences of young women diagnosed with and treated for PID. After providing informed consent, participants completed a brief demographic and health history questionnaire, which was verbally administered by the interviewer. The semi-structured interview was conducted immediately after completion of the questionnaire. Interview questions inquired about topics including the overall experience with PID, thoughts and feelings about the PID diagnosis, coping with the PID diagnosis, social support received after the PID diagnosis, and PID self-management. The questionnaire and interview guide are included in the Appendix. The interviewer allowed flexibility for the interview participants to describe their experiences with PID diagnosis and treatment, following up with questions and probes as needed to explore and clarify the participants' descriptions. Interviews were conducted in an office space on the Johns Hopkins campus that provided privacy. Interview participants were assigned an identification number, and true names or identifying information were removed from interview transcripts. Participants received \$40.00 for their study participation after completing the interview. Interviews were audio recorded and transcribed verbatim. Written field notes were recorded during and after the interviews to capture additional details. Audio-recorded interview files, transcripts, and notes were

reviewed after each interview to determine data saturation and to add reflexivity (i.e., interview guide revisions) prior to the next interview.

Research Variables, Timing of Collection, Definitions, and Measurement

Measures collected at baseline included demographics (e.g., age, race/ethnicity, family/household composition), reproductive and sexual history, and perceived social support. Perceived social support was measured by the Social Provisions Scale (SPS). The SPS contains 24 items, with four items to measure each of the following six social provision dimensions: attachment (emotional closeness from which one derives a sense of security), social integration (a sense of belonging to a group that shares similar interests, concerns, and activities), reassurance of worth (recognition of one's competence, skills, and value by others), reliable alliance (the assurance that others can be counted on for tangible assistance), guidance (advice or information from parental figures, etc.), and opportunity for nurturance (the sense that others rely upon one for their well-being) (Cutrona & Russell, 1987). Using a scale from 1 ("strongly disagree") to 4 ("strongly agree"), respondents indicated the extent to which each item statement described their current relationships with other people (Cutrona & Russell, 1987). SPS scores were determined by calculating the sum totals for each dimension's subscale and the total over all subscales. Higher scores indicated greater levels of perceived social support. Possible scores ranged from 4 to 16 for each SPS subscale, and 24 to 96 for the overall SPS total. As shown in Table 3.1, internal consistency reliability of the total SPS score is excellent ($\alpha = .915$), with alpha coefficients on the individual scales ranging from .653 to .760 (Cutrona & Russell, 1987). In this study, Cronbach's alpha for the total SPS was .89, and ranged from .52 to .78 for SPS subscales. The SPS instrument is shown in the Appendix.

Follow-up measures included parental notification, received social support, and PID self-care behaviors (at 14 days and 30 days). To measure received social support, participants were asked to indicate the types of support their parents/guardians provided after their diagnosis (i.e., provided comfort, offered advice, reminded them to take their medications, took them to follow-up appointments, encouraged them to talk to their partners, or other). This study examined a new variable, coping strategy, as measured by the Brief COPE (Carver, 1997). The Brief COPE, an abbreviated version of the COPE Inventory, is a 28-item instrument used to measure several ways in which people respond to stress. The 14 scales of the Brief COPE measure the following coping strategies: self-distraction (engaging in activities to take one's mind off the stressor), active coping (taking active steps to remove a stressor or to ameliorate its effects), denial (refusal to believe that the stressor exists), substance use (using alcohol or drugs), use of emotional support (using moral support, sympathy, or understanding), use of instrumental support (using advice, assistance, or information), behavioral disengagement (reducing effort to handle the stressor), venting (expressing feelings of distress or upset one is experiencing), positive reframing (managing emotional distress rather managing the stressor), planning (thinking about how to manage a stressor), humor (making fun of the stressful situation), acceptance (belief in the reality of a stressful situation), religion (reliance on religion during a stressful time), and self-blame (blaming self for the stressful situation). Active coping, use of instrumental support, and planning are problem-focused coping strategies, while the remaining coping strategies are emotion-focused (Carver, Scheier, & Weintraub, 1989). The frequency of use for each coping strategy item is measured on a 4-point scale, from 1 ("I haven't been doing this at all") to 4 ("I've been doing this a lot"). Brief COPE scores were determined by calculating

the mean for each scale. Possible Brief COPE scores range from 1 to 4. A higher score indicates a more frequent use of the coping response. According to the author of the Brief COPE, there is no comprehensive score for this measure, and investigators may selectively use the subscales of greatest interest to their research (Carver, 1997). As shown in Table 3.1, internal reliability of the Brief COPE subscales ranges from .50 to .90 (Carver, 1997). Cronbach's alpha in this study ranged from .54 to .93, except acceptance (.27) and self-blame (.49). The Brief COPE instrument is shown in the Appendix.

Data Analysis Plan

To achieve Aim 1, coping strategies were operationalized as Brief COPE scales and descriptively summarized, using frequencies, means, and standard deviations. Types of perceived social support were operationalized as SPS subscales at baseline, and types of received social support were operationalized as parental support reported at follow-up. Social support was descriptively summarized using frequencies, means, and standard deviations.

Data analysis for Aim 2 was performed using Stata I/C, version 15 (StataCorp LP, College Station, TX). Logistic regression was used to analyze relationships between PID self-management behaviors and perceived social support, received social support, and use of coping strategies. The PID self-management behavior outcomes of interest were medication completion, clinical follow-up visit attendance, partner notification, and sexual abstinence. Multiple logistic regression models were constructed for each PID self-management behavior outcome and social support or coping strategy variable, adjusting for age, STI history, health insurance coverage status, and group assignment. Selected covariates were consistent with previously published PID self-management research (Trent et al., 2010). Group assignment was included as a covariate to control for the variable's potential to be a confounder, because

the parent study intervention aimed to improve adherence to the PID treatment recommendations analyzed in this study. Because clinical follow-up assessment was a principal component of the parent study intervention (i.e., all intervention group participants received a community-based clinical follow-up visit), clinical follow-up visit attendance was analyzed only for control group participants, and group assignment was not included as a covariate in multiple logistic regression models to analyze clinical follow-up visit attendance. A significance level of $\alpha = 0.05$ was used for all analyses. Adjusted odds ratios (AORs) and corresponding 95% confidence intervals (CIs) were reported. To test Hypothesis 2.1, bivariate logistic regression analyses were used to screen candidate variables for multiple logistic regression modeling, and multiple logistic regression modeling was used to determine whether young women who reported greater use of problem-focused coping strategies were more likely to report engagement in PID self-management behaviors, controlling for age, STI history, health insurance coverage status, and group assignment. To test Hypothesis 2.2, multiple logistic regression analyses were conducted to determine whether young women who reported higher levels of social support were more likely to report engagement in PID self-management behaviors, controlling for age, STI history, health insurance coverage status, and group assignment. To test Hypothesis 2.3, social support and coping strategy variables with p-values < 0.10 in multiple logistic regression models were selected to create two-way interaction terms to test the moderating effect of social support on the relationship between coping strategies and PID self-management behaviors.

The data analysis approach to achieve Aim 3 was qualitative content analysis, defined as “a research method for the subjective interpretation of the content of text data through the

systematic classification process of coding and identifying themes or patterns” (Hsieh & Shannon, 2005, p. 1278). The audio recording of each interview was reviewed, and general impressions of the interview and noteworthy statements by the participant were documented. The accuracy of all interview transcripts was verified by comparing them to the original audio recordings, and transcripts were read in their entirety to yield a sense of participants’ experiences. Transcripts and field notes were analyzed after each interview to determine data saturation and to add reflexivity (i.e., modification of interview guide questions) prior to the next interview. Verified transcripts were imported into a qualitative research software program, f4analyse, for data management and analysis. Transcribed text related to the focus of the research was selected and grouped by shared characteristics. Codes were generated inductively from the data and from TMSC constructs. Groups of repeating codes or ideas were aggregated into themes. Field notes recorded during the interviews were incorporated into the analyses. Interviews were analyzed throughout the data collection process; therefore, codes, categories, and themes that appeared not to be fully developed in initial interviews were made richer through modifications to the interview guide. The doctoral candidate carried out the principal analysis. Procedures to enhance validity included dual coding and modified member checking (Denzin & Lincoln, 2000). All transcripts were read to create a codebook for relevant text data. A second coder independently coded data by applying the codebook to three transcripts, and the finalized codebook was confirmed by discussion and consensus between the coders. The doctoral candidate and second coder coded three additional transcripts using the finalized codebook, for a cumulative 33% of transcripts analyzed by two coders.

Data Integration Plan

This study employed a convergent mixed methods design. Quantitative and qualitative data were collected and examined separately, and then integrated through narrative at the data interpretation level (Fetters, Curry, & Creswell, 2013). Information from the quantitative and qualitative research phases were weighted equally. The results of quantitative analyses were compared with themes that emerged from the qualitative data. Data integration was achieved by reporting the merged results together as quantitative results followed by participant quotes or qualitative themes that complement the quantitative results. Divergent or inconsistent findings were reported with suggested explanations.

Inclusion of Children

The current study included female children younger than 18 years old who were diagnosed with mild to moderate PID, because children were part of the target age range for the TECH-N study (13-25 years old). At least 20% of PID cases diagnosed each year in the United States occur in adolescents (≤ 19 years old) (Greydanus & Dodich, 2015). Therefore, it is important to include children in studies of PID to identify age-appropriate, effective interventions to prevent adverse reproductive health outcomes for young women so early in their reproductive life course.

Study recruitment sites were facilities designed to serve children, adolescents, and young adults. Participants and TECH-N staff mutually agreed upon appropriate, safe locations for study follow-up visits. Qualitative interviews were conducted in an office space on the campus of an academic health center to allow for safeguarding the privacy of interview participants. With 29 participants who were younger than 18 years old (32%), this study included a sufficient number of children to contribute to a meaningful analysis of the

influences of coping strategies and social support on self-care behaviors among adolescents and young adult women with PID.

A waiver of parental consent was granted for participation in TECH-N—the parent study for this dissertation study—as participants are seeking care for services under the Maryland minor consent law. However, all study participants were encouraged to discuss their participation with a parent, guardian, and/or trusted adult. There were no adverse events related to the TECH-N study using this approach to research with children and/or parental engagement to support the research.

Inclusion of Women and Minorities

All 90 subjects in this study were female. PID is a disease exclusive to females; therefore, males were excluded from TECH-N and the current study. The planned racial distribution of subjects was 96% Black or African American and 4% White. The planned ethnic distribution of subjects was 6% Hispanic or Latino and 94% Not Hispanic or Latino. TECH-N and the current study recruited all young women residing in Baltimore within the target age range, regardless of race/ethnicity. African American women are disproportionately affected by PID (Kreisel, Torrone, Bernstein, Hong, & Gorwitz, 2017), thereby justifying the planned enrollment. Considering previous research experience in this geographic area and the study sites, at least 90% of the young women enrolled in TECH-N and this study were projected to be of African American descent. Cumulative enrollment for this study was 90% Black or African American, 3% White, and 4% more than one race. Ethnic distribution of subjects was 2% Hispanic or Latino and 98% Not Hispanic or Latino.

Protection of Human Subjects

The current study was conducted within the existing infrastructure of an active randomized controlled clinical trial, the TECH-N study. The following will describe details of TECH-N that were pertinent to the current study, as well as additional elements relevant to the qualitative phase of the current study.

Risks to Human Subjects

Human Subjects Involvement, Characteristics, and Design

Subject Population. Ninety adolescents and young adult women aged 13-25 years diagnosed with mild to moderate PID at an academic health center in Baltimore, Maryland were enrolled in the current dissertation study. Children were involved in the study because at least 20% of PID cases diagnosed each year in the United States occur in adolescents (≤ 19 years old) (Greydanus & Dodich, 2015). It is important to include children in studies of PID to identify age-appropriate, effective interventions to prevent adverse reproductive health outcomes for young women so early in their reproductive life course.

Sampling Plan, Recruitment, and Retention Strategies. Adolescents and young adult women with mild to moderate PID were recruited from a large academic health center by the TECH-N research study staff at the time of PID diagnosis. Clinical sites included the adult and pediatric emergency departments and the general pediatrics and adolescent medicine clinics. Research staff were available on-site and accessible via pager to facilitate patient referral and recruitment. Research staff recorded all patients approached for study participation, documenting all referrals, eligible participants, consenting participants, and refusals. To facilitate study participant retention, detailed contact information was obtained from the participant at the time of the initial recruitment, including home and work phone

numbers, cell phone numbers, e-mail addresses, school attended, and the contact information for two individuals who would always know the participants' whereabouts and could be contacted to locate them. Participants were advised to call the TECH-N office if there were changes in their contact information, and they received a \$5 gift card incentive for notification of contact information change. The TECH-N target population resided in Baltimore City at the time of PID diagnosis, but young women who resided in the Baltimore metropolitan area, including surrounding counties, were eligible for study participation.

Inclusion and Exclusion Criteria. Young women 13 to 25 years old, diagnosed with mild to moderate PID, given an outpatient treatment disposition, permanently residing in the Baltimore metropolitan area, and willing to sign informed consent were eligible for study inclusion. Informed consent entailed willingness to complete study procedures, which included randomization and community-based follow-up by the TECH-N team. Patients who were pregnant, had a concurrent diagnosis of sexual assault, or were unable to communicate with staff or use a cell phone due to cognitive limitations, mental disabilities, or English language barriers were ineligible for study participation.

Enrollment, Consent, and Treatment. Recruiters were on-site at the clinical facilities to recruit patients diagnosed with PID at the time of diagnosis. Patients were screened for eligibility criteria, and then recruited for study participation if eligible. Prior to enrollment, study details were reviewed as a part of the informed consent process performed by the recruitment staff. All patients who agreed to participate completed an audio computerized assisted self-interview (ACASI) to collect baseline information and then were randomized to the control or intervention study arm. The ACASI interview was automatically uploaded to a secure server for warehousing in the central database. After

completion of initial TECH-N study procedures and instruction, patients received remuneration of \$10 and a 14-day course of antibiotics consistent with the CDC treatment guidelines to be dispensed by the clinician prior to discharge according to Maryland law and hospital policy.

Qualitative Data Collection. One phase of this study comprised a qualitative exploration of the experiences of young women diagnosed with and treated for PID within the preceding five years. Young women assigned to the control arm of TECH-N were recruited for participation in the qualitative phase of the study. This sampling strategy allowed for in-depth exploration of young women's experiences with PID standard of care treatment. At the completion of the 90-day visit, the TECH-N outreach worker asked control group participants if they were interested in participating in an in-depth interview. Participants who expressed interest were contacted to receive additional information about the interview and for recruitment into the qualitative study. The TECH-N study had IRB approval for continued participant contact beyond the initial 90 days, and participants could indicate their willingness to be contacted for future research studies on the original TECH-N consent form. IRB approval was obtained to conduct the qualitative phase of the research study. During the study recruitment process, the young women were assured that their participation would be strictly voluntary, they could stop at any time, and their study participation decision would not affect their current and/or future care at the academic health center. Interviews were conducted in a space that would allow for the protection of the participant's privacy, where only the participant and interviewer would be present. After providing informed consent, participants completed a brief demographic and health history questionnaire, which was verbally administered by the interviewer. The semi-structured

interview was conducted immediately after completion of the questionnaire. The interviews were audio recorded with a digital recorder, and written field notes were documented. Audio recorded interviews were transcribed. Each participant was assigned a unique study identification (ID) number; personally-identifiable information was not recorded. Participants received \$40.00 after they completed the study visit. Data saturation was reached with 18 interviews, a sample size that was consistent with previously published qualitative research on women diagnosed with PID (Newton et al., 2014).

Sources of Materials

Information regarding demographics, sexual history, attitudes, perceptions, and sexual risk behaviors was collected from participants using ACASI and face-to-face interviews, both structured and semi-structured. ACASI interview data were automatically uploaded to a secure server for warehousing in the central database. Participant records were stored in locked filing cabinets in the locked TECH-N office. All data were linked to participants through a study ID number. Electronic recordings of qualitative interviews were stored on password-protected media and did not include identifying information. The link between identifying information and study ID number were kept in the project manager's locked filing cabinet. To identify and recruit control group participants eligible for the qualitative phase of the study, study team members had access to individually identifiable private information. No persons other than study team members had access to individually identifiable private information.

Potential Risks

There were no significant physical, psychological, financial, legal, or other risks involved in this study. Considering the series of follow-up interviews with participants prior

to recruitment for the qualitative interview, it was not anticipated that participants would experience distress during the qualitative interview focused on experiences with PID. If a participant had expressed a clinical concern and/or emotional distress during the study visit, she would have been referred to a clinician associated with the academic health center for management of reproductive health concerns and/or to her primary care provider for additional services. The general pediatrics and adolescent medicine clinic staff members were available to provide social work and mental health referral services as needed. All interviews were conducted on the campus of the academic health center; therefore, security for study participants and the research team was provided by the campus security team. The potential for breaches of confidentiality was miniscule given the limited number of personnel with access to participant information.

Adequacy of Protection Against Risks

Recruitment and informed consent. Clinical staff referred potential participants to the study by notifying TECH-N staff of adolescent and young adult female patients diagnosed with mild to moderate PID. After the TECH-N team member determined that the patient was eligible for study participation, she met with the patient in a private space (emergency department or clinic examination room) to ask the patient if she was willing to participate in the study. Patients who agreed to participate in the study received a detailed review of the study by a TECH-N team member, including information that their participation in the study would have no effect on subsequent medical care at any referral site. TECH-N participants provided written documentation of informed consent. The TECH-N team obtained a waiver of parental consent from the Johns Hopkins Medicine IRB for participation because Maryland state law permits an adolescent under 18 years old to consent

to research participation while receiving reproductive health care. Further, most adolescents seen in ambulatory sites for PID at Johns Hopkins seek care while unaccompanied by a parent.

For the qualitative interview phase, TECH-N control group participants were contacted after completion of the 90-day visit via telephone, e-mail, and/or mail to inform them of the qualitative research. Participants who expressed interest in being interviewed were scheduled to meet in a private office space on the Johns Hopkins campus for a detailed explanation of the study and the informed consent process. Participants who consented to the interview provided written documentation of informed consent. Parental consent was not required for participation, because the interview pertained to confidential sexual health services. According to Maryland law, a minor has the same capacity as an adult to consent to treatment for or advice about venereal disease [Md. Code Ann., Health-Gen. II § 20-102(c)(1)-(5)]. Under 45 CFR § 46.408 (c), an IRB may waive parental consent requirements if it determines that a research protocol is designed for conditions for which parental or guardian permission is not a reasonable requirement to protect the subjects, an appropriate mechanism for protecting the children who will participate as research subjects will be substituted, and the waiver is not inconsistent with Federal, state, or local law. Furthermore, Maryland law allows for parental bypass in situations of minimal risk and when the burden of getting consent would cause more harm than good. It was asserted that: 1) Many of the issues which were surveyed constituted health problems for which adolescents can seek health care under state regulations without parental consent, thereby making the CFR requirement for parental permission less applicable (45 CFR § 46.402 [a]); 2) Since the consent form stated that the patient had a history of sexual intercourse and STI and/or PID,

seeking permission from parents for adolescents to participate in this interview would represent an automatic disclosure of confidential medical information via the consent form and therefore would violate the Maryland Minor Consent Law [Md. Code Ann., Health-Gen. II § 20-102(c)(1)-(5)]; 3) The requirement of parental consent would impose undue burden on potential participants given their right to privacy related to past sexual behavior and care.

Protections against risk. Only members of the TECH-N evaluation team—all formally trained and committed to confidentiality and protection of patient rights—had access to patient charts and data extraction forms. No identifying patient data have been or will be included in any presentations or publications generated from this study. All TECH-N participants were assigned a unique study ID number to avoid the inclusion of personally identifying information in the TECH-N database. The TECH-N study design provided several alternatives for study participation that allowed adolescents to make decisions about non-participation, participation with parental awareness or involvement, and participation through alternate community outreach strategies. By offering these alternative strategies, our team ensured protection of privacy as afforded by law while setting the stage for adult involvement that could potentially facilitate improved clinical outcomes for the patient. The TECH-N team documented the participation strategies and evaluated potential variations in observed effects based on follow-up approach. To protect the privacy of participants, interviews were conducted in a space that ensured privacy.

Potential Benefits of the Research to Human Subjects and Others

Participants may or may not have directly benefitted from participation in this study, which aimed to identify opportunities for future intervention to enhance PID self-care behaviors and improve reproductive health outcomes among those facing the greatest risk for

negative reproductive health sequelae. Participants who engaged in the qualitative interviews may have found the interviews to be a beneficial opportunity to discuss their health care experience and the issues they encountered in greater depth. The previously mentioned minimal risks were reasonable in relation to the anticipated benefits to research participants and others.

Importance of the Knowledge Gained

Treatment of existing PID episodes and the prevention of future STIs and PID recurrence are critical to reducing the risk of long-term reproductive health complications such as tubal infertility and ectopic pregnancy. This study contributes to the existing knowledge of PID self-care among young women by exploring the context of PID self-care and examining psychosocial factors not addressed in previous studies. Exploring the context of PID self-care behaviors would identify potential opportunities for intervention. Examining psychosocial factors, such as coping and social support, that may influence PID self-care would (1) help clinicians understand, support, and promote self-care among adolescents and young adult women diagnosed with PID, and (2) inform the development of interventions that promote coping strategies and types of social support associated with PID self-care. The minimal risks of participation in this study were reasonable in relation to the importance of the knowledge that may be gained; knowledge gained from this study will advance the identification of priorities to support adolescents and young adult women diagnosed with PID and preserve their reproductive health.

Data and Safety Monitoring Plan

For quality and safety monitoring of the study, the doctoral candidate met monthly with her sponsor, co-sponsors, and faculty mentors to review protocols, recruitment progress,

data collection issues, participant safety, and responses to participants' concerns. She had access to her sponsor and co-sponsor for assistance at any time if she was unable to respond adequately to a participant concern. As a clinical trial, the TECH-N parent study had a data safety monitoring board consisting of a seasoned clinical trial researcher (Cynthia Rand, PhD, Professor, Johns Hopkins University), an adolescent medicine clinician-scientist focused on STI research (Lydia Shrier, MD, MPH, Assistant Professor, Harvard School of Medicine), and a clinician-researcher whose research has focused on treated young women with chronic pelvic pain (Peter Rowe, MD, Professor, Johns Hopkins School of Medicine). Bi-annual data reports generated by the TECH-N biostatistician/data manager were submitted to DSMB team members for review, with written responses requested from each member within two weeks of report submission.

Figure 3.1 Parent Study (TECH-N) Design + Dissertation Data Collection

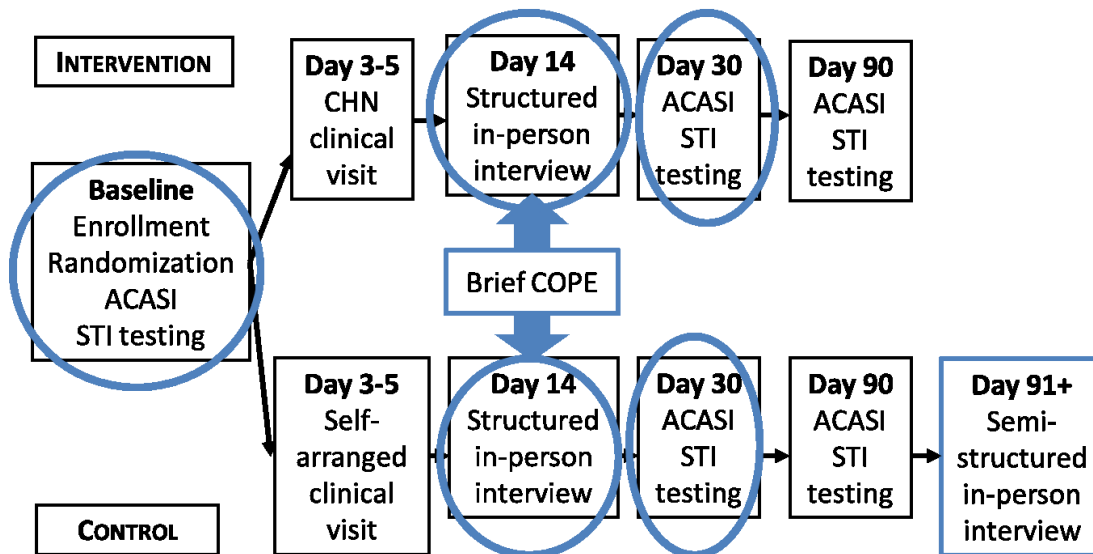


Table 3.1 Summary of Study Instruments

Variable	Theoretical Definition	Operational Definition	Instrument Description	Level of Measurement	Psychometrics	Data Collection Time
Perceived Social Support	The functions of social relationships	Social Provisions Scale (SPS)	24-item scale measuring 6 social provisions, with item responses ranging from 1 (“strongly disagree”) to 4 (“strongly agree”)	Total score (24-96) Subscale score (4-16) Higher score indicates higher perceived support	Internal consistency (total score) = .915 Internal consistency (subscale scores) = .653-.760	Baseline
Coping Strategy	Response to a stressor	Brief COPE	28-item scale measuring 14 coping strategies, with item responses ranging from 1 (“I haven’t been doing this at all”) to 4 (I’ve been doing this a lot”)	Subscale score (1-4) Higher score indicates more frequent use of coping strategy	Internal consistency (subscale scores) = .50-.90	Day 14

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CHAPTER FOUR: MANUSCRIPT TWO

Social Support, Coping Strategies, and Self-Management among Adolescents and Young Adults with Pelvic Inflammatory Disease

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Abstract

Study Objective: To identify social support and coping strategies used by young women diagnosed with pelvic inflammatory disease (PID) and examine their associations with PID self-management.

Design, Setting, Participants, Interventions and Main Outcome Measures: Young women 13-25 years old diagnosed with PID in an urban academic health center emergency department or pediatric clinic (n=90; mean age=19.2 years) completed surveys to assess baseline perceived social support (Social Provisions Scale), and post-diagnosis coping strategies (Brief COPE), received social support, and PID self-management behaviors (medication completion, clinical follow-up visit attendance, partner notification, and sexual abstinence) at follow-up. Multiple logistic regression was used to analyze associations of social support and coping with PID self-management behaviors.

Results: The highest perceived social support was guidance (mean = 12.3, standard deviation [SD]= 2.4). Medication reminders were the most commonly received support (48.9%). Acceptance (mean = 3.5, SD = 0.72) and active coping (mean = 3.5, SD = 0.77) were the most frequently used coping strategies. Coping strategies and received social support were not associated with PID self-management. The social provision of opportunity for nurturance (perceived responsibility for others) was associated with medication completion (adjusted odds ratio [AOR]=1.26, 95% CI: 1.00-1.59, $p=0.05$) and clinical visit attendance (AOR=2.43, 95% CI: 1.19-4.93, $p=0.01$).

Conclusions: Most young women with PID used problem-focused coping strategies after PID diagnosis. Perceived responsibility for others was associated with medication adherence

and clinical visit attendance, but coping strategies and received social support were not associated with adherence to PID treatment recommendations.

Keywords: Pelvic Inflammatory Disease; Self-Management; Adaptation, Psychological; Social Support; Adolescent; Young Adult

Introduction

Treatment regimens recommended by the Centers for Disease Control and Prevention (CDC) for mild to moderate pelvic inflammatory disease (PID) include a 14-day course of outpatient oral antibiotic therapy and pain management, sex partner notification for sexually transmitted infection (STI) treatment, sexual abstinence until patient and partner are treated, and a follow-up evaluation within 72 hours of diagnosis to assess patient for clinical improvement (Centers for Disease Control and Prevention, 2015). Although large randomized clinical trials such as the Pelvic Inflammatory Disease Evaluation and Clinical Health (PEACH) trial have demonstrated that more expensive inpatient antibiotic treatment does not afford additional clinical efficacy compared to outpatient antibiotic treatment for mild to moderate PID (Ness et al., 2002), adherence to the CDC-recommended outpatient treatment regimen remains suboptimal (Trent, 2013). A PEACH trial analysis of medication adherence using electronic event monitoring demonstrated that women took an average of 70% of prescribed doses of doxycycline and took the prescribed two daily doses for less than 50% of outpatient treatment days (Dunbar-Jacob, Sereika, Foley, Bass, & Ness, 2004). Approximately 15% of PEACH trial participants reported failure to abstain from sexual intercourse during the PID treatment period, and approximately 29% reported that their partners received STI treatment after they were diagnosed with PID (Trent et al., 2011).

Compared to their older counterparts, young women diagnosed with PID are at increased risk for subsequent STIs and PID, and adverse reproductive health outcomes (Kelly, Ireland, & Aughey, 2004; Trent, Chung, Forrest, & Ellen, 2008; Trent et al., 2011; Trent, 2013). For example, 20% of adolescent PEACH study participants tested positive for an STI at 30-day follow-up, compared to 5.2% of adult participants (Trent et al., 2011). In a

separate study of adolescents who received outpatient treatment for PID, 34% were diagnosed with chlamydia, gonorrhea, and/or PID during the 48-month follow-up period (Trent et al., 2008). Kelly et al. (2004) conducted a retrospective chart review of young women 13-23 years old diagnosed with PID at an urban teen clinic and found that 23% of the young women did not adhere to the medication regimen and sexual abstinence recommendations. Young women with one PID episode were 1.44 times more likely than young women with recurrent PID to report adherence to treatment recommendations. Acknowledging the limitations of retrospective chart reviews, including the accuracy and thoroughness of clinical documentation and patient self-report, the study results suggest that young women with multiple PID episodes were less adherent to treatment and self-management recommendations than their single-episode peers.

A quality improvement intervention for the outpatient management of PID in adolescents increased the proportion of emergency department and clinic patients who returned for follow-up care within 72 hours from 10% to 43%. However, 57% of patients did not follow up for care, and almost 40% of patients had not completed taking their medications at two weeks (Trent, Judy, Ellen, & Walker, 2006). In a randomized controlled trial of a brief video behavioral intervention for adolescents with mild to moderate PID, only 24% of all patients returned for a 72-hour follow-up clinical visit, and almost one-third of all participants did not adhere to the medication regimen, with no statistically significant differences between the intervention and control groups (Trent, Chung, Burke, Walker, & Ellen, 2010). The limited improvements in outpatient treatment adherence generated by clinical quality improvement and behavioral interventions suggest that factors beyond clinician practices and patient education influence PID self-management.

Coping strategies and social support are two psychosocial factors that may significantly influence PID self-care behaviors among young women. Coping, defined as cognitive and behavioral efforts to manage specific external and/or internal demands appraised as taxing or exceeding the resources of the person, is the attempt to manage psychological stress (Glanz, Rimer, & Viswanath, 2008). Problem-focused coping involves approaching the problem and making active efforts to resolve the problem, while emotion-focused coping includes trying to avoid the problem and focusing on managing the emotions associated with it (Zeidner & Endler, 1996). Social support, or help obtained from others, is a resource for coping and commonly indicated as a strategy on coping instruments (Carver, Scheier, & Weintraub, 1989; Carver, 1997; Glanz et al., 2008; Spirito, Stark, & Williams, 1988). The Transactional Model of Stress and Coping, developed by Lazarus and Cohen, posits that stressful experiences are construed as person-environment transactions, in which the impact of an external stressor, or demand, is mediated by the person's appraisal of the stressor (primary appraisal) and the psychological, social, and cultural resources at the person's disposal (secondary appraisal). Coping mediates the emotional and functional effects of primary and secondary appraisals, and social support moderates the effects of coping strategies on outcomes. Outcomes include health behaviors such as treatment adherence (Glanz et al., 2008). The ways that individuals experience and cope with stress may influence how they seek health care and social support, as well as their adherence to health care professionals' treatment recommendations and follow-up visits (Glanz et al., 2008). During adolescence, individuals move toward independence and autonomy in preparation for adulthood. While the peer group increases in importance, and dependence

upon parents decreases, the family remains a critical source of support during this period, including during times of illness (Muuss, Velder, & Porton, 1996).

There is a dearth of research on coping strategies and social support among young women diagnosed with PID, but a small body of research on coping strategies and social support within the context of related STIs has been published. Young women use multiple coping strategies in response to an STI diagnosis, and the coping strategies differ from the strategies utilized in response to other interpersonal stressors (Baker et al., 2001; Rosenthal, Biro, Cohen, Succop, & Stanberry, 1995). Problem-focused coping has been positively associated with more consistent condom use one month after a chlamydia or gonorrhea diagnosis (Schwartz et al., 2008). Social support has been positively associated with STI-related care seeking (Fortenberry & Zimet, 1999), medication adherence (Scheurer, Choudhry, Swanton, Matlin, & Shrank, 2012), and protective sexual behaviors, such as consistent condom use and secondary abstinence (Crosby et al., 2001; Crosby, DiClemente, Wingood, & Harrington, 2002; Fortenberry & Zimet, 1999; Mazzaferro et al., 2006).

Preliminary analysis from a randomized controlled trial of a technology-enhanced community nurse intervention to prevent recurrent STIs after a PID diagnosis indicated that 65% of young women with PID notified a parent of their diagnosis, and 74% of the young women who notified their parents received support such as advice, comfort, and medication reminders. Young women who reported a greater sense of responsibility for the well-being of others were less likely to notify a parent of their PID diagnosis. Young women who reported a greater sense that they could rely on others, or a greater sense that others recognized their competence and personal qualities were more likely to notify a parent of their PID diagnosis (Munoz Buchanan et al., 2016). Associations between social support and subsequent PID

self-management were not examined. The objectives of this study were to identify the social support and coping strategies used by young women in the immediate interim after a PID diagnosis and to examine the effects of social support and coping strategies on PID self-management. It was hypothesized that social support and problem-focused coping strategies would be positively associated with PID self-management, and that social support would moderate the effects of coping strategies on PID self-management.

Materials and Methods

This study is an analysis of a subsample of participants in the Technology-Enhanced Community Health Nursing (TECH-N) study. As described in previously published research (Butz et al., 2016; Trent et al., 2016), TECH-N was a randomized controlled trial to evaluate an intervention consisting of daily medication reminders via text messaging and a follow-up clinical visit by a community health nurse (CHN) to improve clinical outcomes among young women diagnosed with mild to moderate PID. Study participants were recruited from the pediatric and adult emergency departments and a general pediatrics and adolescent medicine clinic of an academic health center, enrolling in the study on the same day they were diagnosed with PID. Eligible participants were non-pregnant young women aged 13 to 25 years residing in the Baltimore, Maryland metropolitan area, diagnosed with mild to moderate PID, and receiving outpatient PID treatment. Young women who were unable to communicate in English or were admitted into the hospital to receive inpatient PID treatment were excluded from study participation. This analysis includes participants who enrolled in the TECH-N study between June 2015 and December 2016; this period commenced with the addition of an instrument to measure coping to the TECH-N protocol and concluded with the scheduled completion of TECH-N study enrollment. Data were collected via audio computer-

assisted self-interview (ACASI) at baseline and one month, and via structured face-to-face interview at two weeks. The Johns Hopkins Institutions Institutional Review Board approved this study.

Measures

Baseline measures included demographics (e.g., age, race/ethnicity, household composition), reproductive and sexual history, and perceived social support. Follow-up visits collected data on the PID self-management behaviors of medication completion, clinical follow-up visit attendance, partner notification, and temporary abstinence from sexual intercourse, as well as received social support and coping strategies used during the treatment period. To measure received social support, participants were asked to indicate the types of support their parents/guardians (parents) provided after their diagnosis (i.e., provided comfort, offered advice, reminded them to take their medication, took them to the clinical follow-up visit, or encouraged them to talk to their partners).

Perceived social support. Perceived social support, defined as the belief that others are available and desire to help if the individual needs it, was operationalized as the Social Provisions Scale (SPS). The SPS examines the degree to which an individual's social relationships provide various dimensions of social support. The SPS contains 24 items, with four items to measure each of the following six social provision dimensions: attachment, social integration, reassurance of worth, reliable alliance, guidance, and opportunity for nurturance (Cutrona & Russell, 1987). Utilizing a scale ranging from 1 ("strongly disagree") to 4 ("strongly agree"), respondents indicate the extent to which each item statement describes their current relationships with other people. SPS scores are determined by calculating the sum totals for each dimension's subscale and the total over all subscales.

Higher scores indicate greater levels of perceived social support. Possible scores range from 4 to 16 for each SPS subscale, and 24 to 96 for the overall SPS total. Internal consistency reliability of the total SPS score is excellent (Cronbach's $\alpha = 0.915$), with alpha coefficients on the individual scales ranging from 0.653 to 0.760 (Cutrona & Russell, 1987). In this study sample, Cronbach's alpha for the total SPS was 0.89, and ranged from 0.52 to 0.78 for SPS subscales.

Coping strategies. The Brief COPE, a 28-item instrument that measures several ways in which people respond to stress (Carver, 1997), was used to measure coping strategies. The 14 scales of the Brief COPE measure the following coping strategies: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame. Active coping, use of instrumental support, and planning are problem-focused coping strategies, while the remaining coping strategies are emotion-focused (Carver et al., 1989). The frequency of use for each coping strategy item is measured on a 4-point scale, ranging from 1 ("I haven't been doing this at all") to 4 ("I've been doing this a lot"). Brief COPE scores are determined by calculating the mean for each scale, with a possible score range of 1 to 4. A higher score indicates a more frequent use of the coping response. Internal consistency reliability of the Brief COPE scales ranges from 0.50 to 0.90 (Carver, 1997). Cronbach's alpha in this study sample ranged from 0.54 to 0.93, except acceptance (0.27) and self-blame (0.49).

Data Analysis

Descriptive statistics were calculated to summarize the sociodemographic characteristics and sexual/reproductive health history of study participants. Means and

standard deviations of SPS scales and SPS total scores were calculated to measure perceived social support. Received social support was measured by calculating the frequencies of social support acts reported at follow-up. Coping strategies were summarized by calculating the means and standard deviations of Brief COPE scale scores and the relative frequencies of Brief COPE scale mean scores. Logistic regression analysis was utilized to examine relationships between PID self-management behaviors and perceived social support, received social support, and use of coping strategies. The PID self-management behavior outcomes of interest were medication completion, clinical follow-up visit attendance, partner notification, and sexual abstinence. We constructed multiple logistic regression models for each PID self-management behavior outcome and social support or coping strategy variable, adjusting for age, STI history, health insurance coverage status, and group assignment. Selected covariates were consistent with previously published PID self-management research (Trent et al., 2010). Group assignment was included as a covariate to control for the variable's potential to be a confounder; the parent study intervention aimed to improve adherence to the PID treatment recommendations analyzed in this study. Because clinical follow-up assessment was a principal component of the parent study intervention (i.e., all intervention group participants received a community-based clinical follow-up visit), clinical follow-up visit attendance was analyzed only for control group participants, and group assignment was not included as a covariate in clinical follow-up visit multiple logistic regression models. Social support and coping strategy variables with p-values < 0.10 in multiple logistic regression models were selected to create interaction terms to test the moderating effect of social support on the relationship between coping strategies and PID self-management behaviors. A significance level of $\alpha = 0.05$ was used for all analyses. Adjusted odds ratios (AORs) and corresponding

95% confidence intervals (CIs) were reported. Data analysis was performed using Stata I/C, version 15 (StataCorp LP, College Station, TX).

Results

Demographics

The sample for this study consisted of 90 participants who completed the baseline, two-week, and one-month TECH-N study protocol visits. The mean age was 19.2 years (SD = 2.9). Most participants were African American (94.4%), had health insurance (92.3%), and had a primary care provider (68.9%). Approximately 59% of the participants had a positive STI history, and 16.7% had at least one prior PID diagnosis. Approximately 37% of participants reported using any birth control at last intercourse, and 12% used dual protection (i.e., barrier and hormonal contraception) (Table 4.1).

Social Support

The highest levels of perceived social support were within the social provision domains of guidance (mean = 12.3, SD = 2.4) and reliable alliance (mean = 12.1, SD = 2.7), and the lowest were reassurance of worth (mean = 11.4, SD = 2.0) and attachment (mean = 11.7, SD = 2.2). Approximately 68% of participants told a parent about their PID diagnosis, and 88.5% of the young women who told a parent received support from the notified parent. Medication reminders were the most commonly reported support received from a parent (48.9%). One control group participant reported that a parent took her to her clinical follow-up visit (Table 4.2).

Coping Strategies

The most frequently used coping strategies were active coping and acceptance, with subscale mean scores of 3.5 (SD = 0.72) and 3.5 (SD = 0.77) respectively (Figure 4.1).

Observing the frequency of coping strategy use by percentages of corresponding subscale scores, 71% of participants used acceptance “a lot”, and 69% used active coping “a lot” (Table 4.3). The least frequently used coping strategies were substance use (mean = 1.2, SD = 0.68), behavioral disengagement (mean = 1.2, SD = 0.69) and humor (mean = 1.3, SD = 0.76). Most participants indicated that they had not used those coping strategies at all (i.e., subscale score = 1): substance use (88%), behavioral disengagement (87%), humor (84%).

PID Self-Management

At the two-week follow-up visit, 41.1% of participants reported that they had finished taking all the antibiotic pills. Approximately 14% of control group participants attended the clinical follow-up visit. While 89% of participants reported that they notified their sexual partners, 46% reported that their partners had received STI treatment. Twenty-three percent of participants reported that their partners had not been treated for STIs, and 29% did not know if their partners had been treated. Approximately 81% of participants reported that they abstained from sexual intercourse during the two-week treatment period (Figure 4.2). Two participants declined to answer questions about partner notification, partner treatment, and sexual abstinence at two-week follow-up.

Multiple logistic regression models indicated few statistically significant relationships between PID self-management and coping strategies or social support. Medication completion was not associated with any coping strategies examined in this study. Although not statistically significant, there was a trend such that participants who used active coping more frequently were less likely to complete their medications (adjusted odds ratio (AOR) = 0.54; 95% CI: 0.28-1.05; $p = 0.07$). Opportunity for nurturance was the only social provision significantly associated with medication completion (AOR = 1.26; 95% CI: 1.00-1.59; $p =$

0.05); young women with greater perceptions of nurturance (responsibility for others) had 26% higher odds of medication completion. While there were no coping strategies associated with clinical follow-up visit attendance, participants who reported an increased perception of nurturance had 2.43 times higher odds of attending the follow-up visit (95% CI: 1.19-4.93; $p = 0.01$). Regarding partner notification, there were no statistically significant associations with coping strategies or social support. There were trends such that participants who used planning as a coping strategy (AOR = 1.90; 95% CI: 0.94-3.83; $p = 0.07$) and perceived higher levels of social integration (AOR = 1.54; 95% CI: 0.94-2.51; $p = 0.09$) and opportunities for nurturance (AOR = 1.58; 95% CI: 0.95-2.63; $p = 0.08$) were more likely to notify their partners. Sexual abstinence was not associated with any of the coping strategies or social provisions assessed. None of the supportive care received from parents/guardians were significantly associated with PID self-management among the young women.

Discussion

This study examined social support and coping strategies in relation to self-management among young women diagnosed with and treated for PID. Problem-focused coping strategies—active coping and planning—comprised two of the three most frequently used coping strategies in this sample. Active coping was a frequently used coping strategy, which was consistent with behavioral disengagement being one of the least frequently used strategies. Participants did not turn to substance use, limit their efforts to handle the situation, or make fun of their PID diagnosis and treatment to deal with their situation. However, none of the coping strategies examined were significantly associated with the PID self-management behaviors assessed in this sample. That is, use of coping strategies did not significantly differ among young women who did and did not engage in the PID self-

management behaviors of medication completion, clinical follow-up visit attendance, partner notification for treatment, and temporary sexual abstinence.

Although prior studies did not measure coping with PID, some studies examined coping with STIs related to PID. Schwartz et al. (2008) used selected Brief COPE subscales to investigate the coping responses elicited by a diagnosis of chlamydia and/or gonorrhea in a sample of urban, ethnic minority adults. Problem-focused coping comprised the most commonly used strategies, and behavioral disengagement was the least commonly used coping strategy. As with this study, Schwartz et al. (2008) found no associations between coping strategies and partner notification. Rosenthal et al. (1995) used the KIDCOPE, a 10-item standardized instrument developed to assess coping with various kinds of problems, in a study of adolescent girls (mean age = 16.8 years) with a history of at least one STI episode. Results indicated that wishful thinking was the most frequently used coping strategy (95%), followed by problem solving (81%) and emotional regulation (79%). Baker et al. (2001) utilized the KIDCOPE to evaluate whether adolescent girls use similar coping strategies in response to STI acquisition and to an interpersonal stressor, such as a conflict with a friend. Wishful thinking (96%), blaming others (78%), and internal emotional regulation (72%) were the most frequently used coping strategies in response to STI acquisition. Self-blame was used more often in response to STI acquisition than in response to the interpersonal stressor (40% vs. 26%), while problem solving was used less often (43% vs. 58%). The use of different coping instruments and measurement approaches precludes comparisons of coping with STIs by young women in previous studies and coping with PID by young women who participated in this study.

Consistent with prior research, findings from this study identified opportunity for nurturance as a baseline social provision associated with post-diagnosis behavior among young women with PID. Muñoz Buchanan et al. (2016) observed that opportunity for nurturance was negatively associated with parental notification. Young women with an increased sense of responsibility for the well-being of others were less likely to notify a parent of their PID diagnosis. In the current study, opportunity for nurturance was positively associated with medication completion and clinical follow-up visit attendance; young women with an increased sense that others rely on them for their well-being were more likely to complete their medications and attend the clinical follow-up visit. The emergence of opportunity for nurturance in this study suggested that feeling responsible for others is connected to a sense of responsibility for meeting other obligations—such as medication adherence and clinical appointment attendance—among young women diagnosed with and treated for PID. Reassurance and reliable alliance were positively associated with parental notification in the Muñoz Buchanan et al. (2016) study, but no statistically significant relationships between those social provisions and PID self-management were found in the current study sample.

Although young women with higher opportunity for nurturance scores had higher odds of medication adherence or clinical follow-up visit attendance, overall adherence to those PID treatment recommendations was low. Less than 15% of the control group returned for follow-up care within 72 hours, and less than half of all study participants completed the antibiotic therapy as prescribed. While previous PID self-management research has identified unpleasant side effects (e.g., nausea and vomiting) as a reason for medication non-adherence (Dunbar-Jacob et al., 2004; Trent et al., 2006), only six participants—comprising 12% of the

51 participants who did not complete the treatment regimen—reported that they experienced side effects. Partner notification and temporary abstinence rates were high within this study sample, and there were no coping strategies or types of social support associated with increased or decreased adherence to those PID treatment recommendations.

The proportion of participants in the current study who informed a parent of their PID diagnosis (68%) mirrored the 65% proportion noted by Munõz Buchanan et al. (2016). However, fewer participants in the current study reported parental engagement in PID care (60% vs. 74%). Although most of our participants told a parent about their PID diagnosis and subsequently received support from a parent, that support was not associated with adherence to PID treatment recommendations. While this study focused on support received from parents, it must be acknowledged that there are other potential sources of social support (e.g., friends, other relatives) that were not examined in this study.

The current study lays the groundwork for future research aimed at better understanding the coping strategies and social support that affect adherence to PID treatment recommendations among young women. However, several limitations must be considered. All collected data were self-reported by study participants, which introduced the potential for recall bias. Recall bias may have been unintentional due to poor or incomplete memory recall, or intentional due to perceived social desirability. However, data were collected via ACASI, which has been shown to decrease the incomplete or inaccurate reporting of sensitive behaviors such as sexual activity (Ghanem, Hutton, Zenilman, Zimba, & Erbelding, 2005; Rogers et al., 2005). In addition, structured face-to-face interviews were conducted by one outreach worker, whose rapport-building approach facilitated disclosure.

The sample for the current study was recruited from one urban academic health center; therefore, the psychosocial characteristics and self-management behaviors may not be generalizable to young women diagnosed with and treated for PID in other geographic locations or at other types of health care organizations. With a proportion over 90% Black/African American, our sample lacked racial/ethnic diversity. Acknowledging that the lifetime self-reported history of PID diagnosis among non-Hispanic Black and non-Hispanic White sexually experienced women of reproductive age (18-44 years) in the United States with a previous STI diagnosis is nearly equal (10.0 % vs. 10.3%), it is important to include all groups affected by the disease in health promotion research (Kreisel, Torrone, Bernstein, Hong, & Gorwitz, 2017). The relatively small sample size may not have had sufficient power for logistic regression analyses to detect some meaningful differences as statistically significant. Additional research with larger sample sizes is needed to determine whether coping strategies, perceived social support, task-specific support such as medication reminders, and emotional support such as comfort are associated with PID self-management. Despite these limitations, study strengths included conducting the study among young women residing in a community with high STI rates (Maryland Department of Health, 2017) and assessing coping strategies specific to receiving the PID diagnosis and treatment, rather than global coping, dispositional coping, or coping with a hypothetical situation. Additionally, coping strategies were assessed two weeks after PID diagnosis, thus reducing the risk of recall bias. While previous studies concerning adherence to PID treatment recommendations were limited to correlations with demographic characteristics such as age, the current study investigated relationships between PID treatment adherence and psychosocial factors such as situation-specific coping and social support.

Conclusion

PID during adolescence and young adulthood increases vulnerability to long-term adverse reproductive health outcomes and negative health-related quality of life. It is important for interdisciplinary health care providers to understand the roles of psychosocial factors such as coping and social support in PID self-management to develop and implement effective strategies to improve health outcomes among young women with PID. This observational study investigated how social support and coping strategies relate to PID self-management among young women. Previous analyses of PID self-management have been limited to correlations with sociodemographic characteristics such as age, with no examination of the psychosocial barriers to and facilitators of PID self-management. Although additional research is needed to determine relationships with PID self-management behaviors, the results of this study offer an initial suggestion as to which coping strategies and aspects of social support are used by young women diagnosed with and treated for PID.

Table 4.1 Baseline characteristics of young women diagnosed with PID (n = 90)

Characteristic	Number
Age, years (mean, SD)	19.2 (2.9)
Race/Ethnicity	n (%)
African American/Black	85 (94.4)
White	3 (3.3)
Latina/Hispanic	2 (2.2)
Recruitment site	n (%)
Pediatric emergency department	48 (53.3)
Adult emergency department	30 (33.3)
Pediatrics and adolescent medicine clinic	12 (13.3)
Group assignment	n (%)
Intervention	48 (53.3)
Control	42 (46.7)
Has a primary care provider	62 (68.9)
Health insurance	n (%)
Medicaid	77 (85.6)
Private	6 (6.7)
None	7 (7.8)
Lives with family member(s)	77 (85.6)
Sexual history	mean (SD)
Lifetime male partners	5.7 (4.7)
Male sex partners in last 3 months	1.5 (0.9)
History of STI	53 (58.9)
History of pregnancy	46 (51.1)

Table 4.2 Social support reported by participants (n = 90)

Perceived social support - Social Provisions Scale	Mean (SD)	Range
Guidance	12.3 (2.4)	6-16
Reassurance of worth	11.4 (2.0)	8-16
Social integration	11.9 (1.9)	8-16
Attachment	11.7 (2.2)	7-16
Opportunity for nurturance	11.8 (2.0)	8-16
Reliable alliance	12.1 (2.7)	4-16
Social Provisions Scale total	71.3 (10.1)	52-96
Received social support	n (%)	
Told parent/guardian about PID diagnosis	61 (67.8)	
Received supportive care from parent/guardian	54 (60.0)	
Support received from parent/guardian	n (%)	
Reminders to take medication	44 (48.9)	
Comfort	29 (32.2)	
Advice	26 (28.9)	
Encouragement to talk to partner	9 (10.0)	
Took to clinical follow-up visit ^a	1 (2.4)	

a: Control group only

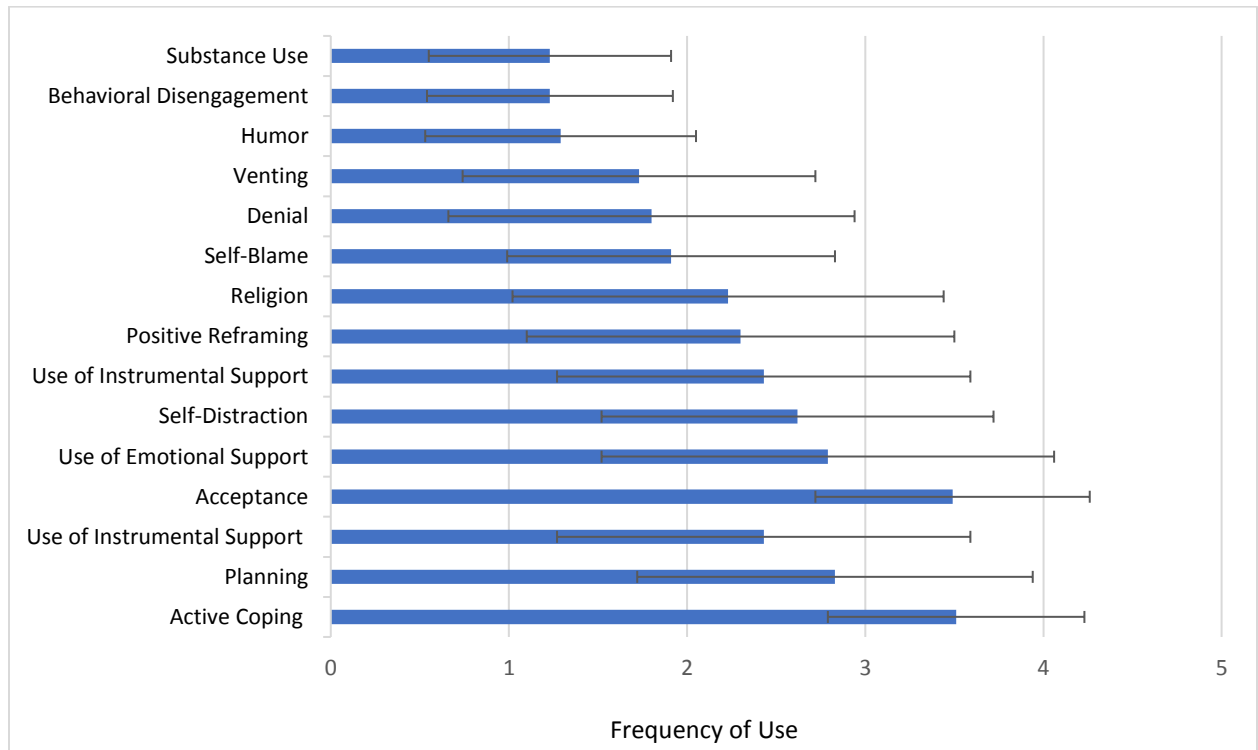
Table 4.3 Coping strategy use frequency (n = 90)

Coping Strategy	% of Participants			
	Not at all	A little bit	A medium amount	A lot
<i>Problem-Focused</i>				
Active coping	1	8	22	69
Planning	16	12	28	44
Use of instrumental support	26	20	24	30
<i>Emotion-Focused</i>				
Acceptance	2	6	21	71
Use of emotional support	24	12	13	51
Self-distraction	21	16	30	33
Positive reframing	33	19	19	29
Religion	39	14	20	27
Self-blame	38	23	29	10
Denial	59	12	10	19
Venting	52	20	17	11
Humor*	84	4	7	4
Behavioral disengagement	87	8	1	4
Substance use	88	2	7	3

Coping strategy scores: "Not at all" = 1; "A little bit" = 1.5-2; "A medium amount" = 2.5-3; "A lot" = 3.5-4

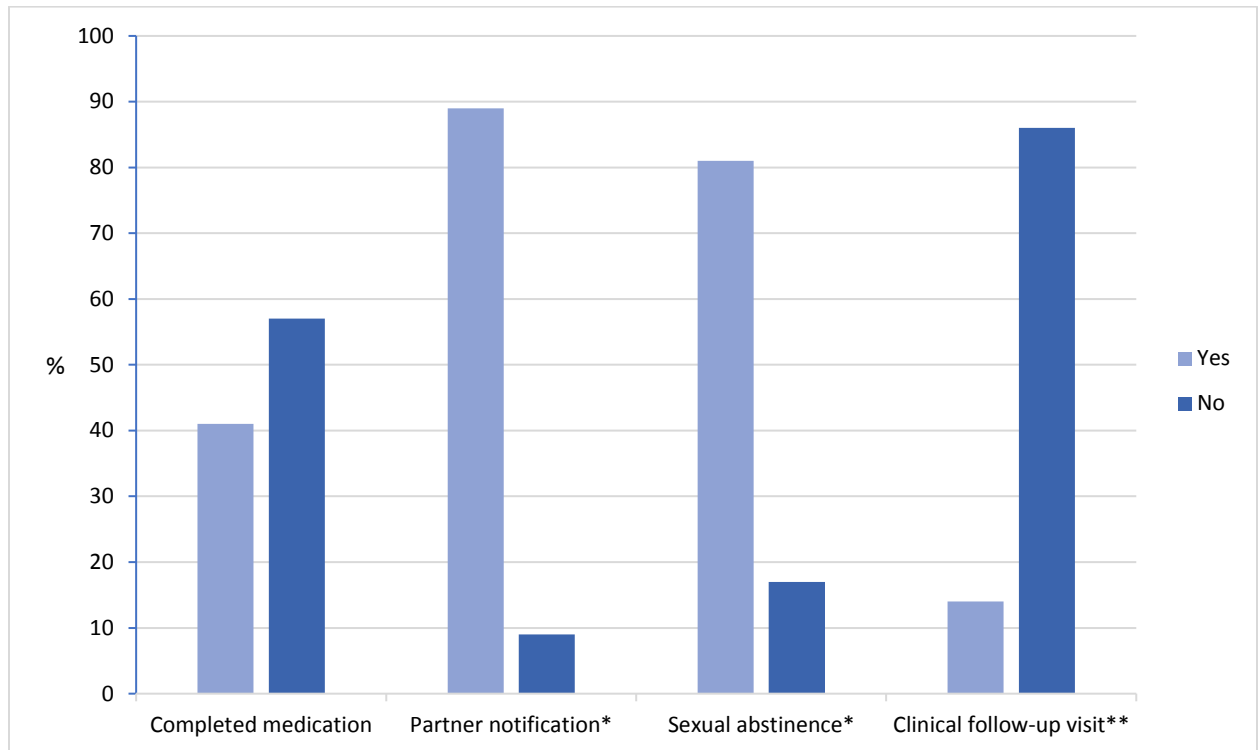
*Less than 100% due to rounding

Figure 4.1 Coping Strategies Used by Young Women Diagnosed with PID (n = 90)^a



Frequency of Use legend: 1 = I haven't been doing this at all; 2 = I've been doing this a little bit; 3 = I've been doing this a medium amount; 4 = I've been doing this a lot
a: Error bar represents one standard deviation

Figure 4.2 PID Self-Management Reported at 2-Week Follow-Up (n = 90)



*: 2 participants did not answer

** : Control group participants only (n = 42)

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CHAPTER FOUR ADDENDUM: INSTRUMENT INTERNAL CONSISTENCY

RELIABILITY

Table 4.4 Social Provisions Scale Reliabilities

Provision	α (Current Study)	α (Russell & Cutrona, 1987 ^a)
Attachment	0.53	0.747
Social Integration	0.63	0.673
Reassurance of Worth	0.52	0.665
Reliable Alliance	0.78	0.653
Guidance	0.70	0.76
Opportunity for Nurturance	0.57	0.655
Total Social Provision Score	0.89	0.915

a: Reliability values from the original study are provided for reference.

Table 4.5 Brief COPE Reliabilities

Coping Strategy	α (Current Study)	α (Carver, 1997 ^a)
Self-distraction	0.65	0.71
Active coping	0.54	0.68
Denial	0.85	0.54
Substance use	0.93	0.90
Use of emotional support	0.84	0.71
Use of instrumental support	0.69	0.64
Behavioral disengagement	N/A ^b	0.65
Venting	0.63	0.50
Positive reframing	0.75	0.64
Planning	0.56	0.73
Humor	0.89	0.73
Acceptance	0.27	0.57
Religion	0.75	0.82
Self-blame	0.49	0.69

a: Reliability values from the original study are provided for reference.

b: Unable to calculate due to a transcription error that rendered 1 of the 2 scale items invalid.

CHAPTER FIVE: MANUSCRIPT THREE

Coping with Pelvic Inflammatory Disease Self-Management: A Mixed Methods Study of Urban Adolescents and Young Adult Women

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Abstract

Pelvic inflammatory disease (PID) during adolescence and young adulthood increases vulnerability to long-term adverse reproductive health outcomes and negative health-related quality of life. Nonadherence to PID treatment recommendations increases risk for subsequent sexually transmitted infections (STIs) and recurrent PID. Limited improvements in outpatient PID treatment adherence generated by interventions focused on clinician practices, patient education, and behavioral modeling suggest that psychosocial factors, such as coping, may influence self-management behaviors. This convergent mixed methods study of 18 urban young women diagnosed with PID used descriptive statistics to analyze perceived social support, coping strategies, social support received from parents, and PID self-management behaviors (medication adherence, clinical follow-up visit attendance, partner notification, and sexual abstinence). Semi-structured interviews were conducted to explore the experiences of young women diagnosed with and treated for PID. Quantitative and qualitative data were integrated at the data interpretation level. Acceptance and active coping were the most frequently used coping strategies. Upon learning about their diagnosis, young women were motivated to ameliorate PID, often with support from family and friends. PID self-management was incorporated into their daily routine. Survey results indicated that most young women notified their partners and abstained from sex during the treatment period, but adherence to the medication completion and clinical follow-up visit attendance recommendations was relatively low. However, the interviews revealed that some young women completed their medication and/or returned for follow-up after the recommended period. Assessing young women's perceptions of PID and coping resources can inform best practices for successful PID treatment.

Keywords

adolescent, coping, pelvic inflammatory disease, self-management, social support

Introduction

Each year, approximately 800,000 cases of pelvic inflammatory disease (PID) are diagnosed in the United States (Greydanus & Dodich, 2015). PID comprises a spectrum of inflammatory disorders of the female upper genital tract that arise from genital infections commonly attributed to sexually transmitted organisms, such as *Neisseria gonorrhoeae* (GC) and *Chlamydia trachomatis* (CT) (Centers for Disease Control and Prevention, 2015; Handsfield, 2011). PID poses a long-term threat to reproductive health, with complications that include chronic pelvic pain, ectopic pregnancy, and tubal infertility (Brunham, Gottlieb, & Paavonen, 2015; Greydanus & Dodich, 2015). The current standard of care for treatment of mild to moderate PID as recommended by the Centers for Disease Control and Prevention (CDC) includes a 14-day course of outpatient oral antibiotic therapy and pain management, partner notification for treatment, sexual abstinence until patient and partner are treated, and a follow-up evaluation within 72 hours of diagnosis to assess for clinical improvement (Centers for Disease Control and Prevention, 2015).

Large clinical trials such as the Pelvic Inflammatory Disease Evaluation and Clinical Health (PEACH) study demonstrated that inpatient delivery of antibiotic therapy was not superior to outpatient antibiotic treatment for mild to moderate PID, which prompted the CDC to recommend outpatient treatment for mild to moderate PID. However, self-management among young women with respect to adherence to the CDC-recommended outpatient treatment regimen is suboptimal, thereby increasing the risk for adverse reproductive health outcomes (Trent, 2013b). Medication adherence measured by electronic event monitoring in a subgroup of PEACH study participants demonstrated that women took an average of 70% of prescribed doses of doxycycline (Dunbar-Jacob, Sereika, Foley, Bass,

& Ness, 2004; Trent, Judy, Ellen, & Walker, 2006). Approximately 29% of all PEACH study participants reported that their partners received STI treatment after their PID diagnosis, and approximately 15% reported failure to abstain from sexual intercourse during the PID treatment period (Trent et al., 2011). A retrospective chart review of adolescents diagnosed with PID at an urban teen clinic indicated that 23% of patients did not adhere to the medication regimen and sexual abstinence recommendations. Girls with a history of one PID episode were 1.44 times more likely than girls with recurrent PID to report adherence to treatment recommendations, suggesting that adolescents with recurrent PID were less adherent to treatment and self-management recommendations than their single-episode peers (Kelly, Ireland, & Aughey, 2004). Compared to their older counterparts, adolescents and young women diagnosed with PID are at increased risk for subsequent STIs and PID, and adverse reproductive health outcomes. At 30-day follow-up, 20% of adolescent PEACH study participants tested positive for an STI, compared to 5.2% of adult participants (Trent et al., 2011). Although the CDC (2015) identifies adolescents as a special population in the STD Treatment Guidelines, there are no special considerations for PID treatment among adolescents. Analyses of PEACH trial data led to the conclusion that inpatient treatment for mild to moderate PID would not be cost-effective for patients of any age. However, the PEACH trial had low representation among patients in early and middle adolescence: The mean age of participants younger than 19 years was 17.8 (SD = 1) years, which suggests that PEACH trial findings related to the effectiveness of outpatient treatment and self-management may not be applicable to younger adolescents (Trent, 2013a).

While the proportion of adolescent emergency department (ED) and clinic patients who returned for follow-up care increased from 10% to 43% after the implementation of a

quality improvement intervention for the outpatient management of PID, 57% of patients did not follow up for care within 72 hours, and almost 40% of patients had not completed taking their medications at two weeks post-diagnosis. In structured follow-up telephone interviews, 47% of patients did not identify what prevented them from following up for care, and 20% could not provide a reason for their failure to complete the prescribed medication regimen (Trent et al., 2006). In a randomized controlled trial of a brief video behavioral intervention for adolescents with mild to moderate PID, only 24% of all patients returned for a 72-hour follow-up clinical visit, and almost one-third of all participants did not complete their medications, with no statistically significant differences between the intervention and control groups (Trent, Chung, Burke, Walker, & Ellen, 2010). The limited improvements in outpatient treatment adherence generated by clinical quality improvement and behavioral interventions suggest that factors beyond clinician practices, patient education, and behavioral modeling influence PID self-management. Psychosocial factors—particularly coping strategies and social support—may influence self-management behaviors among young women diagnosed with PID, and therefore warrant exploration.

This study aimed to explore the self-management experiences of urban adolescents and young adult women diagnosed with PID and examine the coping strategies utilized during the PID treatment period. The Transactional Model of Stress and Coping (TMSC), a framework for evaluating processes of coping with stressful events, was used to guide this study. Developed by Lazarus and Cohen, the TMSC posits that stressful experiences are construed as person-environment transactions, in which the impact of an external stressor, or demand, is mediated by the perceived significance of the stressor (primary appraisal) and the psychological and social resources at the person's disposal (secondary appraisal). Coping

strategies mediate the emotional and functional effects of primary and secondary appraisals. Outcomes of the coping process are a person's adaptation to a stressor, after appraising the situation and resources and being influenced by coping efforts (Glanz, Rimer, & Viswanath, 2008). The coping outcomes of interest for the current study include the following PID self-management behaviors: medication adherence, clinical follow-up visit attendance, partner notification, and sexual abstinence during the treatment period.

Methods

This study is an analysis of a subsample of participants in the Technology-Enhanced Community Health Nursing (TECH-N) study. As described in previously published research (Butz et al., 2016; Trent et al., 2016), TECH-N was a randomized controlled trial to evaluate an intervention consisting of daily medication reminders via text messaging and a follow-up clinical visit by a community health nurse (CHN) to improve clinical outcomes among young women diagnosed with PID. Study participants were recruited from the pediatric and adult EDs and a general pediatrics and adolescent medicine clinic of an academic health center in Baltimore, Maryland and enrolled in the study on the same day they were diagnosed with PID. This analysis includes participants who enrolled in the TECH-N study between June 2015 and December 2016; this period commenced with the addition of an instrument to measure coping to the TECH-N protocol and concluded with the scheduled completion of TECH-N study enrollment. The sample for this study consisted of young women 13 to 25 years of age who received standard of care treatment for mild to moderate PID, selected from the cohort of TECH-N control group participants who completed the 90-day protocol visit. Purposive sampling of control group participants supported the exploration of young women's experiences with PID diagnosis and treatment that were not influenced by the

TECH-N intervention. Quantitative data were collected via audio computer-assisted self-interview (ACASI) at baseline and one month, and via structured face-to-face interview at two weeks. Qualitative data were collected via one-time, in-person, semi-structured interviews. The study was approved by the Johns Hopkins Institutions institutional review board.

Measures

Baseline measures included demographics (e.g., age, race/ethnicity, household composition), reproductive and sexual history, and perceived social support. During follow-up visits, data were collected on the PID self-management behaviors of medication completion, clinical follow-up visit attendance, partner notification, and temporary abstinence from sexual intercourse, as well as received social support and coping strategies used during the treatment period. To measure received social support, participants were asked to indicate the types of support their parents/guardians provided after their diagnosis (i.e., provided comfort, offered advice, reminded them to take their medication, took them to the clinical follow-up visit, or encouraged them to talk to their partners).

Perceived social support. Perceived social support, defined as the belief that others are available and desire to help if the individual needs aid, was operationalized as the Social Provisions Scale (SPS). The SPS examines the degree to which an individual's social relationships provide various dimensions of social support. The SPS contains 24 items, with four items to measure each of the following six social provision dimensions: attachment, social integration, reassurance of worth, reliable alliance, guidance, and opportunity for nurturance (Cutrona & Russell, 1987). Using a scale from 1 ("strongly disagree") to 4 ("strongly agree"), respondents indicate the extent to which each item statement describes

their current relationships with other people. SPS scores are determined by calculating the sum totals for each dimension's subscale and the total over all subscales. Higher scores indicate greater levels of perceived social support. Possible scores range from 4 to 16 for each SPS subscale, and 24 to 96 for the overall SPS total. Internal consistency reliability of the total SPS score is excellent (Cronbach's $\alpha = 0.915$), with alpha coefficients on the individual scales ranging from 0.653 to 0.760 (Cutrona & Russell, 1987).

Coping strategies. The Brief COPE, a 28-item instrument that measures several ways in which people respond to stress (Carver, 1997), was used to measure coping strategies. The 14 scales of the Brief COPE measure the following coping strategies: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame. Active coping, use of instrumental support, and planning are problem-focused coping strategies, while the remaining coping strategies are emotion-focused (Carver, Scheier, & Weintraub, 1989). The frequency of use for each coping strategy item is measured on a 4-point scale, from 1 ("I haven't been doing this at all") to 4 ("I've been doing this a lot"). Brief COPE scores are determined by calculating the mean for each scale. Higher scores indicate more frequent use of the coping response. Internal consistency reliability of the Brief COPE scales ranges from 0.50 to 0.90 (Carver, 1997).

Qualitative data. Utilizing a qualitative descriptive approach (Sandelowski, 2000), the semi-structured interview guide included open-ended questions to explore the experiences of young women diagnosed with and treated for PID. Interview questions inquired about topics including the overall experience with PID, thoughts and feelings about

the PID diagnosis, coping with the PID diagnosis, social support received during the PID treatment period, and PID self-management. After providing informed consent, participants completed a brief demographic and health history questionnaire, which was verbally administered by the interviewer. The semi-structured interview was conducted immediately after completion of the questionnaire. Participants received \$40.00 remuneration at the completion of the interview. Interviews were audio recorded and transcribed verbatim. Written notes were recorded during and after the interviews to capture additional details. Transcripts, audio recordings, and notes were reviewed after each interview to determine data saturation and to add reflexivity (i.e., interview guide revisions) prior to the next interview.

Data Analysis

Quantitative data. Descriptive statistics were calculated to summarize the sociodemographic characteristics and sexual/reproductive health history of study participants. Means and standard deviations of SPS scales and SPS total scores were calculated to measure perceived social support. Received social support was measured by calculating the frequencies of social support activities reported at follow-up. Coping strategies were summarized by calculating the means, standard deviations, and frequencies of Brief COPE scale scores. Stata I/C, version 15 statistical analysis software (StataCorp LP, College Station, TX) was used to analyze data.

Qualitative data. Data were analyzed using a qualitative content analysis procedure (Hsieh & Shannon, 2005). Transcripts and field notes were analyzed after each interview to determine data saturation and to add reflexivity prior to the next interview. Verified transcripts were imported into a qualitative research software program, f4analyse, for data management and analysis. Transcribed text related to the focus of the research was selected

and grouped by shared characteristics. For this study, codes were derived from TMSC concepts and PID self-management behaviors. Groups of repeating codes or ideas were aggregated into categories. Field notes recorded during the interviews were incorporated into the analyses. Interviews were analyzed throughout the data collection process; codes, categories, and themes that appeared not to be fully developed in initial interviews were made richer through modifications to the interview guide. The first author read all transcripts and created a codebook for all relevant text data. A second coder independently coded data by applying the codebook to three transcripts, and the finalized codebook was confirmed by discussion and consensus between the coders. The first author and second coder independently coded three additional transcripts using the finalized codebook and discussed their analyses, for a cumulative 33% of transcripts analyzed by a second coder. The first author analyzed all interview transcripts.

Integration of quantitative and qualitative data. Data were organized and evaluated for patterns in participant descriptions of PID self-management behaviors by Brief COPE scores (coping) and SPS scores (social support). Quantitative and qualitative results were integrated in narrative by using quotes from the interviews to illustrate the PID self-management behaviors of the study participants and related coping strategies.

Results

Participants

The study sample consisted of 18 young women who completed TECH-N study protocol visits and an in-depth, in-person semi-structured qualitative interview. Two-week data were missing for two participants. Mean age at PID diagnosis was 18.2 years ($SD = 2.1$), and mean age at the time of the interview was 19.2 years ($SD = 1.9$). On average, participants

were interviewed approximately 9 months (mean = 9.4, SD = 5.4) after receiving the PID diagnosis. The amount of time that passed between PID diagnosis and interview participation ranged from 3 to 21 months. Most participants were African American (89%), had health insurance (94%), and had a primary care provider (PCP) (78%). At baseline, approximately 78% of the participants had a positive STI history, and 39% had at least one prior PID diagnosis. Approximately 44% of participants reported using any birth control at last sexual intercourse prior to PID diagnosis, and 11% used dual protection (i.e., barrier and hormonal contraception) (Table 5.1).

Primary and Secondary Appraisals of PID

Primary appraisal. Few participants were familiar with PID prior to receiving their diagnosis, and the young women who had heard of PID had limited knowledge of the disease. Finding out that the abdominal pain that prompted them to seek medical attention was caused by something called “pelvic inflammatory disease” evoked confusion and fear. Some young women were afraid because they thought PID was a permanent illness, as expressed by 18-year-old Rose (pseudonyms used for study participants): *“I thought it was something that wouldn't go away. I was scared, I didn't know what to do.”* Initial confusion and fear gave way to shock, sadness, and anger when the young women found out that PID came from having an STI.

Secondary appraisal. Secondary appraisal includes the perceived ability to change the situation and expectations about the effectiveness of one's coping resources (Glanz et al., 2008). After learning about their diagnosis, young women were confident in their ability to

change the situation (i.e., “get rid of” PID): *“I felt relieved because then I was like ‘Okay, at least I know it’s something I can get rid of.’”* (Rose, 18 years old)

Coping resources include social support, and the highest levels of perceived social support for the young women were within the social provision domains of reliable alliance (mean = 13.1, SD = 2.3) and guidance (mean = 12.9, SD = 1.9). The lowest were reassurance of worth (mean = 12.0, SD = 1.4) and attachment (mean = 12.1, SD = 1.9) (Table 5.2).

Explaining why she told her mother and aunt about her PID diagnosis, 17-year-old Violet believed it was important for them to know about it, and she anticipated receiving much-needed support from them: *“I felt like it was a big deal. I just felt like they both should have known and I’m really horrible at taking medication, so I needed somebody to remind me to take my medication.”*

Coping

The most frequently used coping strategies were acceptance and active coping: 94% of participants used acceptance “a lot”, and 69% of participants used active coping “a lot.” The least frequently used coping strategies were behavioral disengagement, substance use, and humor. Most participants indicated that they had not used those coping strategies at all (i.e., subscale score = 1): behavioral disengagement (94%), substance use (88%), humor (88%) (Table 5.3). After diagnosis, participants aimed their attention at active steps to ameliorate PID. Planning and active coping primarily focused on taking medication: *“I wanted to get rid of it. I wanted to get rid of it, so I just was like, I had set up a schedule of the time to take the medicine.”* (Lily, 18 years old)

Most participants (72%) told a parent about their PID diagnosis and subsequently received support from a parent in the form of comfort (72%), medication reminders (50%),

advice (33%), and/or encouragement to talk to partners (17%). Approximately 70% of participants reported using instrumental support (e.g., advice, information) or emotional support (e.g., reassurance) a medium amount or a lot to cope with having PID. Young women revealed in the interviews that they also received support from other family members, friends, and partners, as 18-year-old Daisy described support from her best friend:

She called me every morning "Hey you take your medicine?" And at night, "Hey you took your medicine?" Sometimes I just felt like I didn't want to get out the bed so [she would say] "I'mma come over. You don't have to get out the bed, we can watch movies."

Although study participants disclosed their PID diagnosis to trusted persons and subsequently received support, many of the young women concealed the physical and emotional burdens of PID that they experienced:

I just acted like a regular, normal person. Like if nothing ever happened. But I knew deep down inside. Like my inside was hurting. Like I was upset. I was crushed on the inside, but the outside you couldn't, you wouldn't be able to tell. I was a regular happy person. Keep smiling. Nobody knew I was going through anything but me.

(Ivy, 16 years old)

PID Self-Management

Study participants described experiences with pain, the emotional stress of PID and STI diagnoses, and distasteful medicine, but those difficulties did not deter the young women from engaging in PID self-management. They were self-motivated to get rid of PID. Participants described incorporating PID self-management into their lives as part of their daily routine—such as taking a dose of medicine upon waking and before going to bed.

There were no apparent patterns in PID self-management behaviors according to SPS and Brief COPE scores.

Medication adherence. At two-week follow-up, 56% of participants reported that they had completed the antibiotic therapy. Non-adherence could not be attributed to lack of knowledge, as 89% correctly recalled the number of days they were advised to take the medications. The discrepancy between reported medication adherence and PID treatment knowledge may be attributed to young women inadvertently extending the length of time for medication completion. While all participants disclosed during their interview that they took all pills that were dispensed to them, some of them described taking longer than the recommended 14 days to finish taking the medicine. Delayed or missed doses were largely unintentional, and the young women were concerned about the potential consequences of missing a dose:

I went on vacation to West Virginia and I didn't bring my medicine with me. I stayed there for the weekend, so I was kind of freaking out when I realized I didn't bring my medicine with me. I couldn't do anything but when I got back, I asked if it was okay if I could double dose, but I didn't . . . She said don't double dose the medicine, so I just took my medicine for that day when I got back and then I just kept taking it as regular. I just had to take it for longer than what I would have to. (Violet, 17 years old)

Remembering to take the medication on time was difficult for some young women, and they worried that missing a dose or taking a dose late would render the PID treatment ineffective. Lily (18 years old) expressed, “*Yeah it's easy to forget. It's so easy to forget. So, if I forget, I feel like I mess up. I don't want to mess up, because I wanted it [PID] gone.*”

Young women described using memory aids such as alarms, but they also relied on others to remind them to take their medicine. Quantitative data indicated medication reminders as the support most commonly received from a parent (50%), and qualitative data revealed that young women also received medication reminders from other relatives, friends, and boyfriends.

Medication completion was the priority PID self-management behavior among the young women, who understood the importance of finishing an antibiotic regimen:

I guess just the most important thing is just finishing your medicine, even if you feel better, because I think a lot of people ... they just think once they're feeling better they can just stop taking it. But you have to finish it all, for it all to work. (Holly, 19 years old)

There was high expectancy attributed to medication adherence. Participants trusted that finishing the medicine dispensed to them would cure their PID: *“As long as you take the medicine, you’re good.”* (Iris, 18 years old)

Clinical follow-up visit attendance. At the TECH-N two-week protocol visit, only three participants (17%) reported that they had attended a clinical follow-up visit within 72 hours of PID diagnosis. One participant reported that a parent accompanied her to the follow-up visit. One-month follow-up data suggest a disconnection between PID treatment recommendations and the patient education received and retained by young women: Four participants (22%) correctly recalled that they were advised to return for follow-up clinical evaluation within 72 hours after diagnosis. The most frequently selected response was two weeks after diagnosis (56%). Data indicated that young women sought clinical evaluation more than the CDC-recommended 72 hours after PID diagnosis: By one-month follow-up,

only three participants reported that they had not attended a clinical follow-up visit. Among participants who returned for follow-up more than 72 hours after PID diagnosis, some of them revealed that they already had an upcoming scheduled appointment with their PCP when they were diagnosed. They decided to wait for that appointment to inform their PCP of their PID diagnosis. Camellia (20 years old) explained that it made more sense to her to return for follow-up after she finished taking her medicine:

Well, I really wanted to finish the pills first, and I didn't just want to run up there and still be there and not be able to know why, because I hadn't finished the medication so I'm just like, it would make more sense to me if I just wait until after the medication and that way they can check and make sure it's completely gone.

Reasons for never returning for follow-up included the lack of an available appointment with the PCP and forgetting to schedule the appointment.

Partner notification. Two weeks after PID diagnosis, 88% of participants reported that they notified their sexual partners of their PID diagnosis, and 63% of them reported that their partners had received STI treatment. By the time they were interviewed, 94% of participants had notified their partners, who were current and former boyfriends, casual partners, and a husband. Young women informed their partners about PID and the connection to STIs and advised them to seek medical attention (“*You need to get checked*”). Partner notification was accusatory for some participants (“*You gave me something*”), while others used a non-confrontational approach. No participants expressed fear related to notifying partners. The one participant who did not notify her partner was no longer in contact with him by the time she was diagnosed with PID, and she was unable to locate him. During their

relationship, her partner told her that he was routinely tested for STIs; therefore, she believed that he should have been tested and treated in the meantime:

I haven't been talking to him for a minute, so I don't . . . I don't know exactly where he is at all. He don't have a social media or anything. His phone is off. I don't know, I haven't talked to him . . . But he claimed that he get check-ups every three months . . . It's been longer [than three months] since I talked to him. (Lily, 18 years old)

Sexual abstinence. Approximately 81% of participants reported that they abstained from sexual intercourse during the two-week treatment period. Some young women disclosed that it was easy to adhere to the sexual abstinence recommendation because they were not sexually active around the time of PID diagnosis, and sex was not that important to them. Participants also described abstaining from sex because they were upset with their partners for betraying their trust and infecting them with an STI. They continued to abstain after the treatment period because they were afraid of contracting another STI and getting PID again. Trusting their partner was a concern:

I was really scared to have sex after that honestly. Even though I knew he was clean, I think that was something an issue that we have with our relationship. I was scared he was going to go back out and cheat on me and get something again and just give it right back to me or something along those lines, so I was just kinda like . . . I really don't want to have sex with you right now. (Violet, 17 years old)

Discussion

This observational study explored self-management among young urban women diagnosed and treated for PID, within the context of coping. Problem-focused coping strategies—active coping and planning—comprised two of the four most frequently used

coping strategies. Self-management was driven by a personal desire to cure PID, and young women incorporated the tasks of PID self-management into their daily lives. Young women often received support from parents, friends, partners, and other trusted persons during the PID treatment period.

Though no previously published research has measured coping with PID, a few studies have examined coping with STIs that may cause PID. Schwartz et al. (2008) selected Brief COPE subscales to investigate the coping responses elicited by a diagnosis of chlamydia and/or gonorrhea in a sample of urban, ethnic minority men and women. Problem-focused coping (identified by Schwartz and colleagues as a distinct coping strategy) was the most commonly used strategy, and behavioral disengagement was the least commonly used coping strategy. Using the KIDCOPE, a 10-item standardized instrument developed to assess coping with various kinds of problems, Rosenthal et al. (1995) found that wishful thinking (95%) was the strategy most frequently used by adolescent girls to cope with an STI, followed by problem solving (81%) and emotional regulation (79%). Also using the KIDCOPE, Baker et al. (2001) found that adolescent girls most frequently used wishful thinking (96%), blaming others (78%), and internal emotional regulation (72%) in response to STI diagnosis. The use of different instruments that do not measure the same collection of coping strategies precludes direct comparisons of coping with STIs by young women in previous studies and coping with PID by young women in this study.

Most participants told a parent about their PID diagnosis and subsequently received support from a parent. This is consistent with previous research, such as Munõz Buchanan et al. (2016) who found that 65% of young women informed a parent of their PID diagnosis and 74% of those young women received supportive care from a parent. During the interviews,

participants described receiving social support (e.g., medication reminders) that they directly attributed to their adherence to PID treatment recommendations. While previous research has focused on support received from parents, this study explored additional sources of social support, including friends, partners, and other relatives. Study participants revealed that young women who did not disclose their PID diagnosis to a parent confided in other trusted persons who supported them throughout the treatment period. Thus, PID diagnosis counseling should include an assessment of the young woman's coping resources and diagnosis disclosure plans. Asking a young woman who she plans to tell about her PID diagnosis would reveal potential sources of emotional and/or instrumental support. Young women who are unable to identify trusted family members, friends, or other persons may need self-management support from nurses throughout the treatment period. Personalized PID self-management support could include outreach or extended communication in the form of periodic phone calls, text messages, or other electronic communication to check on the young women and provide encouragement. Having a system in place for clinicians to receive and respond to contact initiated by the young women would also be beneficial.

Previous research has shown that a PID diagnosis can be a distressing experience for women, primarily due to worry about long-term reproductive health (Newton et al., 2014). Our findings suggest that the stress of the PID diagnosis does not prevent young women from engaging in PID self-management, because they are motivated by the belief that PID can be cured. PID treatment adherence varied by type of self-management behavior. While partner notification and temporary sexual abstinence rates were high, slightly more than half of all study participants had completed the antibiotic therapy as prescribed by two-week follow-up, and only three participants returned for follow-up care within 72 hours. Previous PID self-

management research has identified unpleasant effects such as nausea and vomiting as reasons for medication non-adherence (Dunbar-Jacob et al., 2004; Trent et al., 2006). Qualitative interviews revealed that participants in the current study experienced similar issues, but they employed strategies to manage them and complete the prescribed course of antibiotics. Medication completion sometimes took longer than 14 days because of missed doses. Most participants were assessed by a clinician within one month after diagnosis, but few had returned for follow-up evaluation within the recommended three days after initiation of antibiotic therapy.

This study contributes to understanding the coping strategies that affect adherence to PID treatment recommendations among young women and lays the groundwork for future research. However, several limitations must be considered. All collected data were self-reported by study participants, which introduced the potential for recall bias. Recall bias may have been unintentional due to poor or incomplete memory recall, or intentional due to perceived social desirability. However, some data were collected via ACASI, which has been shown to decrease the incomplete or inaccurate reporting of sensitive behaviors such as sexual activity (Ghanem, Hutton, Zenilman, Zimba, & Erbelding, 2005; Rogers et al., 2005). Further, study team members engaged in rapport-building to increase participants' comfort with sharing information during face-to-face quantitative and qualitative data collection. All participants were recruited from one urban academic health center; therefore, the psychosocial characteristics and self-management behaviors may not be generalizable to young women diagnosed with and treated for PID in other geographic locations or at other types of health care organizations. The sample was approximately 90% Black/African American, so it lacked racial and ethnic diversity. Despite these limitations, study strengths

included the examination of PID self-management behaviors within the context of coping. Previous analyses of PID self-management have been limited to correlations with sociodemographic characteristics such as age, with no examination of the psychosocial barriers to and facilitators of PID self-management. The current study assessed coping strategies specific to PID diagnosis and treatment, rather than global coping, dispositional coping, or coping with a hypothetical situation. Coping strategy use was assessed approximately two weeks after PID diagnosis, which reduced the risk of recall loss. In-depth interviews elucidated the self-management behaviors of young women diagnosed with PID, providing context that is not accessible via quantitative data collection. Previous qualitative research on PID was limited to the experiences of women 18 years of age and older, but the current study explored the perspectives and experiences of adolescents as young as 14 years of age.

Conclusion

PID during adolescence and young adulthood increases vulnerability to long-term adverse reproductive health outcomes and negative health-related quality of life (Brunham, Gottlieb, & Paavonen, 2015; Greydanus & Dodich, 2015). It is important for interdisciplinary health care providers to understand the roles of coping and other psychosocial factors in PID self-management to develop and implement effective strategies to improve health outcomes among young women with PID. Self-management of PID is an interpersonal process, as it requires the adoption of protective sexual behaviors to prevent STI reinfection and may involve other persons for care and support. PID diagnosis counseling provides an important opportunity for clinicians to assess young women's perceptions of PID and resources to manage PID, clarify and/or reinforce information, and offer encouragement related to PID

self-management. The results of this study suggest that the use of problem-focused coping strategies and social support may facilitate PID self-management among young women. Clinicians and young women should work together to develop a PID self-management plan that can be incorporated into daily life in accordance with CDC treatment recommendations.

Table 5.1 Demographic characteristics of young women diagnosed with PID (n = 18)

	Mean	SD	Range
Age (years)	18	2	14-23
Lifetime male partners	5	4	
Male sex partners in last 3 months	1	1	
Race/Ethnicity	n	%	
African American/Black	16	89	
White	1	6	
Latina/Hispanic	1	6	
Recruitment site			
Pediatric emergency department	11	61	
Adult emergency department	4	22	
Pediatrics and adolescent medicine clinic	3	17	
Has a primary care provider	14	78	
Health insurance			
Medicaid	16	89	
Private	1	6	
None	1	6	
Lives with family member(s)	16	89	
History of STI	14	78	
History of pregnancy	9	50	

Table 5.2 Perceived social support reported by participants (n = 18)

Social Provisions Scale	Mean	SD	Range
Guidance	12.9	1.9	9-16
Reassurance of worth	12.0	1.4	9-15
Social integration	12.3	2.2	8-16
Attachment	12.1	1.9	10-16
Opportunity for nurturance	12.2	1.9	9-16
Reliable alliance	13.1	2.3	10-16
Social Provisions Scale total	74.1	7.9	60-88

Table 5.3 Frequency of coping strategy use (n = 16*)

Coping Strategy	% Participants			
	Not at all	A little bit	A medium amount	A lot
<i>Problem-Focused</i>				
Active coping	6%	6%	19%	69%
Planning	6%	25%	19%	50%
Use of instrumental support	25%	6%	38%	31%
<i>Emotion-Focused</i>				
Acceptance	0%	0%	6%	94%
Self-distraction	25%	0%	19%	56%
Use of emotional support	19%	13%	19%	50%
Positive reframing	25%	25%	19%	31%
Religion	44%	25%	13%	19%
Self-blame	38%	19%	25%	19%
Denial	75%	13%	6%	6%
Venting	50%	25%	19%	6%
Humor	88%	6%	0%	6%
Behavioral disengagement	94%	6%	0%	0%
Substance use	88%	6%	6%	0%

Brief COPE score categories: “Not at all” (1); “A little bit” (1.5-2); “A medium amount” (2.5-3); “A lot” (3.5-4)

*Data missing for 2 participants

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CHAPTER FIVE ADDENDUM

“My body, my business” – Diagnosis Disclosure in the Context of Pelvic Inflammatory Disease Self-Management

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Purpose

Partner notification is a critical component of the national recommendations for pelvic inflammatory disease (PID) treatment and secondary prevention of sexually transmitted infections (STIs). Diagnosis disclosure to persons beyond sexual partners may have implications for PID self-management among adolescents and young adult (AYA) women, who often rely on family and others for support. Little is known about persons selected by AYA for diagnosis disclosure, reasons for disclosure, and disclosure outcomes. The purpose of this study was to explore diagnosis disclosure among PID-affected AYA to better understand the context of disclosure and illness management.

Methods

In-depth semi-structured interviews were conducted with a purposive sample of 18 AYA (13-25 years old) diagnosed with and treated for PID in the emergency department or a general pediatrics and adolescent medicine clinic within an academic health center in Baltimore, Maryland. All potential participants contacted were enrolled in the control arm of a randomized controlled trial to improve outcomes after PID diagnosis. Prior to the interview, participants completed a structured questionnaire to collect demographic, social, and sexual health history information. Interview queries included persons selected for diagnosis disclosure, disclosure content, rationale for disclosure or nondisclosure, and responses to disclosure. Interviews were audio-recorded, transcribed, and uploaded to f4analyse for analysis. Content analysis was used to interpret text data and identify categories and themes.

Results

At the time of the interview, the median age of participants was 19.5 years (range: 15-23) and median time since PID diagnosis was 9 months (range: 3-21). The median age at PID diagnosis was 18 years (range: 14-23). Three themes related to PID diagnosis disclosure emerged from the interviews. The main theme was *need-to-know*; participants disclosed only to persons whom they believed should know about the diagnosis. Participants' perceptions of an individual's need to know also shaped the information they disclosed about the diagnosis. Adhering to clinicians' recommendations, participants disclosed the diagnosis to their sexual partners with the intent to prevent STI reinfection and PID recurrence. Two additional themes that emerged were *seeking support without judgment* and *protecting privacy*. Participants portrayed most parents and select other family members and friends as persons whom they could rely on for nonjudgmental support. To explain nondisclosure, they often discussed a belief that few people could be trusted not to divulge their diagnosis to other people. Participants described responses to disclosure that were supportive (e.g., reassurance) and unsupportive (e.g., rejection). However, all participants received emotional and/or instrumental support from at least one person after diagnosis disclosure, and they highly valued that support.

Conclusions

PID diagnosis disclosure is influenced by AYA's perceptions of an individual's need to know about the diagnosis to promote PID self-management and/or provide support. AYAs carefully consider the anticipated outcomes of the disclosure in determining "need to know" status.

Sources of Support

National Institute of Nursing Research (Award Numbers R01NR013507 [Trent] and F31NR016397 [Tillman]), Jonas Center for Nursing and Veterans Healthcare (Tillman)

Educational Objective

To describe diagnosis disclosure among adolescents and young adult women diagnosed with and treated for PID, in the context of self-management.

MeSH Keywords

Pelvic Inflammatory Disease, Self Disclosure, Self Care, Adolescent Medicine, Young Adult

CHAPTER SIX: DISCUSSION

Summary

Although effective PID treatment and subsequent prevention of recurrent STIs and PID are important for fertility preservation and improving health-related quality of life (Brunham et al., 2015; Greydanus & Dodich, 2015), many young women diagnosed with PID do not fully adhere to the CDC treatment recommendations (A. M. Kelly et al., 2004; Trent et al., 2011). The limited improvements in outpatient treatment adherence generated by quality improvement and behavioral interventions in clinical settings suggest that factors beyond clinician practices, patient education, and behavioral modeling influence PID self-management. Psychosocial factors—particularly coping strategies and social support—may influence self-management behaviors among young women diagnosed with PID, but to our knowledge, no studies have investigated the roles of coping and social support in PID treatment adherence among young women. The current study used a convergent mixed methods design approach to examine and explore the coping strategies, social support, and self-management behaviors of young women diagnosed with PID during the two-week treatment period. Problem-focused coping strategies, such as active coping, comprised the coping strategies most frequently used during the PID treatment period. However, none of the coping strategies examined were significantly associated with the PID self-management behaviors assessed in the study sample. Although young women with an increased sense of responsibility for others (i.e., a higher SPS opportunity for nurturance score) were more likely to complete their medications and attend the clinical follow-up visit, overall adherence to those PID treatment recommendations was low: Less than half of all study participants completed the antibiotic therapy as prescribed, and less than 15% of the participants who

received standard of care PID treatment (i.e., TECH-N control group participants) returned for follow-up care within 72 hours. Qualitative findings revealed that upon learning about their diagnosis, study participants were motivated to mobilize their resources to ameliorate PID. Instrumental and emotional support from family and friends facilitated PID self-management. The young women incorporated PID self-management into their lives as part of their daily routine, which may or may not have been consistent with the prescribed medical protocol. Some young women extended PID treatment beyond the recommended period; that is, they took longer than 14 days to finish the antibiotic medication and/or returned for follow-up care more than 72 hours after diagnosis. The implications of patient deviations from treatment recommendations on clinical outcomes are unclear.

Strengths and Limitations

The current study had several limitations that were considered. All collected data were self-reported by study participants, which introduced the potential for recall bias. Recall bias may have been unintentional due to poor or incomplete memory recall, or intentional due to perceived social desirability. However, the use of ACASI has been shown to decrease the underreporting of sensitive data, including data related to sexual/reproductive health (Ghanem, Hutton, Zenilman, Zimba, & Erbelding, 2005; Rogers et al., 2005). Further, study team members engaged in rapport-building to increase participants' comfort with sharing information during face-to-face quantitative and qualitative data collection. The relatively small sample size may not have had sufficient power to detect some meaningful differences as statistically significant. Study results were based on a sample of RCT participants from one urban academic health center and therefore may not be generalizable to other groups of young women who do not have access to similar clinical support services. Of note, at the

time of TECH-N study enrollment, all participants received a full 14-day course of PID medications at no monetary cost to them, thereby eliminating financial and physical barriers to obtaining treatment (and subsequent medication adherence) that young women outside this study could encounter.

The major strength of this study was the use of a mixed methods design to enhance contextual understanding of PID self-management among young women who resided in a community with high STI rates (Maryland Department of Health, 2017). While previous studies concerning adherence to PID treatment recommendations have been limited to correlations with demographic characteristics such as age, the current study investigated relationships between PID treatment adherence and psychosocial factors such as situation-specific coping and social support. In-depth interviews with young women diagnosed with and treated for PID elucidated the processes of PID self-care, providing insights that could not be gained from quantitative data.

Contributions to Science

In this study, quantitative and qualitative data were collected and analyzed to identify relationships between coping strategies, social support, and adherence to PID treatment recommendations. Psychosocial factors that promote or hinder PID self-management among young women were not examined in previous studies. The current study explored PID self-management among a group at elevated risk for PID recurrence and reproductive complications—young women residing in an urban area with high STI prevalence—to reveal successes as well as opportunities to improve adherence to PID treatment recommendations. The current study also advanced the representation of adolescents in PID self-management research. While published qualitative research on PID has reported on the experiences of

women 18 years of age and older, this study explored the experiences of adolescents as young as 14 years old.

Practice and Policy Implications

PID during adolescence and young adulthood increases vulnerability to long-term adverse reproductive health outcomes and negative health-related quality of life. It is important for interdisciplinary health care providers to understand the roles of psychosocial factors, such as coping and social support, in PID self-management to develop and implement effective strategies to improve health outcomes among young women with PID. Qualitative results suggest that the PID diagnosis should be accompanied by an assessment of the patient's appraisals of PID and her plans and resources for PID self-management. This would grant clinicians an opportunity to clarify and/or reinforce information and offer encouragement related to PID self-management. The low rate of 72-hour follow-up visit attendance among study participants and their subsequent interview responses indicate the need for improved patient education related to clinical follow-up visit attendance, which should include an explanation for returning for clinical evaluation within 72 hours of PID diagnosis and initiation of treatment. Clinicians should assist with access to follow-up care for young women who do not have a primary care provider or encounter barriers to making a follow-up appointment with their primary care provider. In the context of administrative policy, it is important for primary care providers to have appointment times available for short-notice scheduling of clinical follow-up visits. Some interview participants described attempting to schedule a 72-hour follow-up appointment with their primary care provider and being told that there were no available appointments during that period, and that they had to schedule an appointment at least one month in advance.

Study results indicated that feeling responsible for the well-being of others is associated with medication adherence and clinical appointment attendance. Therefore, connecting PID self-management to young women's sense of responsibility for others may increase adherence to PID treatment recommendations. Study findings also revealed that participants understood the importance of completing an antibiotic treatment regimen, even if they missed a scheduled dose, thus indicating the positive influence of patient education and clinician encouragement on medication adherence. Nurses are positioned for vital roles in PID diagnosis counseling and personalized PID self-management support. PID diagnosis counseling should include an assessment of the young woman's coping resources and diagnosis disclosure plans. Asking a young woman who she plans to tell about her PID diagnosis would reveal potential sources of emotional and/or instrumental support. Young women who are unable to identify trusted family members, friends, or other persons may need self-management support from nurses throughout the treatment period. Personalized PID self-management support could include outreach or extended communication in the form of periodic phone calls, text messages, or other electronic communication to check on the young women and provide encouragement. It would also be beneficial to have a system in place to receive and respond to contact initiated by the young women. Community health nursing could also be used to deliver personalized PID self-management support by meeting the women where they reside and bringing the clinical care and health promotion to them.

Recommendations for Future Research

The current study lays the groundwork for future research aimed at understanding the influences on PID treatment adherence among young women. Additional quantitative research with larger sample sizes in diverse settings is needed to determine whether coping

strategies, perceived social support, task-specific support such as medication reminders, and emotional support such as comfort are associated with PID self-management. Longitudinal studies that collect coping and social support data at multiple points during the treatment period would enhance understanding of their roles in PID self-management over time. Qualitative research to explore experiences with PID diagnosis and treatment in diverse populations and settings would provide a more comprehensive view of PID self-management among young women. Future study samples should reflect the racial/ethnic diversity of PID incidence and prevalence. Acknowledging that the lifetime self-reported history of PID diagnosis among non-Hispanic Black and non-Hispanic White sexually experienced women of reproductive age (18-44 years) in the United States with a previous STI diagnosis is nearly equal (10.0 % vs. 10.3%) (Kreisel, Torrone, Bernstein, Hong, & Gorwitz, 2017), it is important for health promotion research to include all groups affected by the disease. Future research should examine other factors in addition to coping and social support (e.g., self-esteem) for more comprehensive analyses of the psychosocial influences on PID self-management among young women, which may inform the development of effective care plans to subsequently improve sexual/reproductive health outcomes and quality of life across the lifespan.

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APPENDIX: STUDY INSTRUMENTS

Social Provisions Scale

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Instructions: In answering the following questions, think about your current relationships with friends, family members, co-workers, community members, and so on. Please indicate to what extent each statement describes your current relationships with other people. Use the following scale to indicate your opinion.

<u>STRONGLY DISAGREE</u>	<u>DISAGREE</u>	<u>AGREE</u>	<u>STRONGLY AGREE</u>
1	2	3	4

So, for example, if you feel a statement is very true of your current relationships, you would respond with a 4 (strongly agree). If you feel a statement clearly does not describe your relationships, you would respond with a 1 (strongly disagree).

- | | <u>Rating</u> |
|---|---------------|
| 1. There are people I can depend on to help me if I really need it. | _____ |
| 2. I feel that I do not have close personal relationships with other people. | _____ |
| 3. There is no one I can turn to for guidance in times of stress. | _____ |
| 4. There are people who depend on me for help. | _____ |
| 5. There are people who enjoy the same social activities I do. | _____ |
| 6. Other people do not view me as competent. | _____ |
| 7. I feel personally responsible for the well-being of another person. | _____ |
| 8. I feel part of a group of people who share my attitudes and beliefs. | _____ |
| 9. I do not think other people respect my skills and abilities. | _____ |
| 10. If something went wrong, no one would come to my assistance. | _____ |
| 11. I have close relationships that provide me with a sense of emotional security and well-being. | _____ |
| 12. There is someone I could talk to about important decisions in my life. | _____ |
| 13. I have relationships where my competence and skill are recognized. | _____ |
| 14. There is no one who shares my interests and concerns. | _____ |

Social Provisions Scale – 1

	<u>Rating</u>
15. There is no one who really relies on me for their well-being.	_____
16. There is a trustworthy person I could turn to for advice if I were having problems.	_____
17. I feel a strong emotional bond with at least one other person.	_____
18. There is no one I can depend on for aid if I really need it.	_____
19. There is no one I feel comfortable talking about problems with.	_____
20. There are people who admire my talents and abilities.	_____
21. I lack a feeling of intimacy with another person.	_____
22. There is no one who likes to do the things I do.	_____
23. There are people who I can count on in an emergency.	_____
24. No one needs me to care for them.	_____

Scoring:

A score for each social provision is derived such that a high score indicates that the individual is receiving that provision. Items that are asterisked should be reversed before scoring (i.e., 4=1, 3=2, 2=3, 1=4).

1. Guidance: 3*, 12, 16, 19*
2. Reassurance of Worth: 6*, 9*, 13, 20
3. Social Integration: 5, 8, 14*, 22*
4. Attachment: 2*, 11, 17, 21 *
5. Nurturance: 4, 7, 15*, 24*
6. Reliable Alliance: 1, 10*, 18*, 23

Social Provisions Scale - 2

Brief COPE

These items (sentences) deal with ways you have been coping with the stress in your life since you found out you had pelvic inflammatory disease (PID). There are many ways to try to deal with problems. These items ask what you have been doing to cope with PID.

Different people deal with things in different ways, but we are interested in how you have tried to deal with PID. Each item says something about a particular way of coping. We want to know how much you have been doing what the item says. Please do not answer based on whether it seems to be working or not—just whether or not you are doing it. Please use the response choices provided below. Try to rate each item separately from the others. Make your answers as true FOR YOU as you can.

Response Choices

- 1 = I haven't been doing this at all
- 2 = I've been doing this a little bit
- 3 = I've been doing this a medium amount
- 4 = I've been doing this a lot

Items

- 1. I have been turning to work or other activities to take my mind off things.
- 2. I have been concentrating my efforts on doing something about the situation I am in.
- 3. I have been saying to myself, "This isn't real."
- 4. I have been using alcohol or other drugs to make myself feel better.
- 5. I have been getting emotional support from others.
- 6. I have been giving up trying to deal with it.
- 7. I have been taking action to try to make the situation better.
- 8. I have been refusing to believe that it has happened.
- 9. I have been saying things to let my unpleasant feelings escape.
- 10. I have been getting help and advice from other people.
- 11. I have been using alcohol or other drugs to help me get through it.
- 12. I have been trying to see it in a different light, to make it seem more positive.
- 13. I have been criticizing myself.
- 14. I have been trying to come up with a strategy about what to do.
- 15. I have been getting comfort and understanding from someone.
- 16. I have been giving up the attempt to cope.
- 17. I have been looking for something good in what is happening.
- 18. I have been making jokes about it.
- 19. I have been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
- 20. I have been accepting the reality of the fact that it has happened.
- 21. I have been expressing my negative feelings.
- 22. I have been trying to find comfort in my religion or spiritual beliefs.
- 23. I have been trying to get advice or help from other people about what to do.
- 24. I have been learning to live with it.
- 25. I have been thinking hard about what steps to take.
- 26. I have been blaming myself for things that happened.

- 27. I have been praying or meditating.
- 28. I have been making fun of the situation.

Scales (computed with no reversals of coding)

Self-distraction, items 1 and 19

Active coping, items 2 and 7

Denial, items 3 and 8

Substance use, items 4 and 11

Use of emotional support, items 5 and 15

Use of instrumental support, items 10 and 23

Behavioral disengagement, items 6 and 16

Venting, items 9 and 21

Positive reframing, items 12 and 17

Planning, items 14 and 25

Humor, items 18 and 28

Acceptance, items 20 and 24

Religion, items 22 and 27

Self-blame, items 13 and 26

Adapted from <http://www.psy.miami.edu/faculty/ccarver/sclBrCOPE.html>

Qualitative Interview Guide

1. Tell me about your experience with PID.

- a. *Finding out, severity, previous knowledge (STI-PID connection), HCP info & interactions, told anyone*
 - i. *When the MD/RN told you that you had PID, what was the first thought that came to mind? How bad did you think it was?*
- b. *Some women say they feel sad, angry, dirty, or other ways when they find out that they have PID, other women say they don't feel anything at all. How did you feel when you found out you had PID?*
- c. *[If difficulty expressing] How would you compare PID to other challenges that you have had?*

2. What did you do after you found out you had PID?

- a. *Next move after you left the ED/clinic/MD office*
- b. *There are many ways to try to deal with problems, and different people deal with problems in different ways, like trying to figure out a way to fix the problem, trying not to think about it, denying that anything really happened, getting support from other people, or giving up trying to deal with it. How did you try to deal with having PID?*
- c. *What/Who helped and how*

3. Tell me about a typical day for you while you were being treated for PID.

- a. *Work/school, Rx routine and challenges, follow-up visit, recall non-typical day*
- b. *At what point in time did you feel like your PID was over (no longer a problem)? Do you feel like PID is still an issue for you? Are you still having any problems related to PID?*

4. I'd like to ask you about your sexual activity after you found out you had PID. Can you tell me about it?

- a. *Partner(s) and relationship(s), notification & treatment, sexual activity change, condoms*

5. What would you say was the hardest part about taking care of your PID?

6. What was the easiest part about taking care of your PID?

7. Knowing what you know now about having PID, if you could go back to the day you found out you had PID, what advice would you give to yourself?

8. Years ago, women with PID had to stay in the hospital until their pain got better. How would it have affected you if the doctor had decided that you needed to stay in the hospital?

9. Before we end the interview, is there anything else you would like to say, or anything else you would like for me to know about your experience with PID?

- a. *What should nurses and doctors know about young women taking care of PID at home?*

Pre-Interview Questionnaire
Administer verbally to participants

Demographic and Social Information

1. How did you find out about this study?
 - a. Phone call
 - b. E-mail
 - c. Flyer
 - d. TECH-N outreach worker (Jackie)
2. Date of birth
3. How old are you?
4. With which race(s)/ethnicity do you identify? Select all that apply.
 - a. Black/African American
 - b. White/European American
 - c. Native American/Pacific Islander
 - d. Asian
 - e. Hispanic
 - f. Other _____
5. If more than one race/ethnicity, with which do you identify the most?
 - a. Black/African American
 - b. White/European American
 - c. Native American/Pacific Islander
 - d. Asian
 - e. Hispanic
 - f. Other _____
6. What is the highest level of education you have completed?
 - a. Are you currently in school?
 - i. Which grade/level/classification?
 - ii. Where?
7. What is your mother's highest level of education?
8. Do you currently have a job?
 - a. Full-time or part-time?
9. Did you have a job around the time you had PID?
 - a. Full-time or part-time?
10. Do you currently have health insurance?
 - a. Name of health insurance plan

11. Did you have health insurance when you had PID?
 - a. Name of health insurance plan
12. With whom do you currently live?
13. With whom were you living when you had PID?
14. If you needed help with something important, whom would you count on?
15. Were you in a relationship around the time you had PID?

Health Information

1. Date of PID diagnosis
2. Age at PID diagnosis
3. Do you have a primary care provider (doctor or clinic)?
 - a. Name?
4. At which health care facility were you diagnosed with PID?
5. Did you take all of the antibiotic pills that were given to you for PID?
 - a. If not, around how many pills were left over?
6. Did you take any medicine for pain relief while you had PID?
 - a. What pain medicine did you take?
 - i. Tylenol/acetaminophen
 - ii. Advil/Motrin/ibuprofen
 - iii. Aleve/naproxen sodium
 - iv. Other
7. Did you go back to see a doctor or other health care provider within 3 days after you were diagnosed with PID?
 - a. If yes, where did you go for your follow-up visit?
 - b. If no, did you see a doctor at any point while you were being treated for PID?
8. How many times have you had PID?
9. Have you ever had any of the following sexually transmitted infections? How many times? Before or after PID? (*Document in table below*)
 - a. No prior STIs
 - b. Chlamydia
 - c. Gonorrhea
 - d. Trichomonas vaginalis

- e. Mycoplasma genitalium
- f. Genital herpes
- g. Genital warts/HPV
- h. HIV
- i. Syphilis
- j. Other

STI	Before PID	After PID
Chlamydia		
Gonorrhea		
Trichomonas vaginalis		
Mycoplasma genitalium		
Genital Herpes		
Genital warts/HPV		
HIV		
Syphilis		
Other		

10. How old were you the first time you had sex?

11. How many sexual partners have you had in your lifetime?

- a. Male
- b. Female

12. How many sexual partners have you had in the last three months?

- a. Male
- b. Female

13. Which form(s) of birth control did you use the last time you had sex?

- a. Pill
- b. Patch
- c. Implant
- d. IUD
- e. Depo-Provera
- f. Condom
- g. Withdrawal
- h. Tubal ligation
- i. Male sterilization
- j. Other
- k. None

14. Which form(s) of birth control were you using around the time you were diagnosed with PID?

- a. Abstinence
- b. Pill

- c. Patch
- d. Implant
- e. IUD
- f. Depo-Provera
- g. Condom
- h. Withdrawal
- i. Tubal ligation
- j. Male sterilization
- k. Other
- l. None

15. How many times have you been pregnant? (*Document in table below*)
- a. Was the pregnancy before or after PID?
 - b. What were the outcomes of those pregnancies?

Pregnancy	Before PID	After PID	Outcome
1			
2			
3			
4			
5			
6			

CURRICULUM VITAE

Part I

PERSONAL DATA

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EDUCATION

Year	Degree	Institution	Location
2018	PhD	Johns Hopkins University	Baltimore, MD
2006	BSN	Medical University of South Carolina	Charleston, SC
2003	MPH	University of South Carolina	Columbia, SC
2002	BS	Florida State University	Tallahassee, FL

LICENSE AND CERTIFICATION

Year	Source	Type	License Number	Expiration Date
2006	South Carolina Board of Nursing	Registered Nurse	105587	4/30/20
2017	American Heart Association	Basic Life Support (BLS) for Healthcare Providers		9/30/19

PROFESSIONAL EXPERIENCE

Year	Position	Institution	Location
2012-present	Clinical Research Nurse	National Institutes of Health	Bethesda, MD
2015-2016	Research Assistant	Johns Hopkins University	Baltimore, MD
2011-2012	Registered Nurse	Palmetto Health	Columbia, SC
2010-2011	Registered Nurse II	University of South Carolina	Columbia, SC
2009-2010	Clinical Quality Improvement Coordinator	South Carolina Primary Health Care Association	Columbia, SC

2008-2009	Charge Nurse	Eau Claire Cooperative Health Centers, Inc.	Columbia, SC
2007-2008	Registered Nurse	Palmetto Health	Columbia, SC
2004-2005	Administrative Post-Graduate Fellow	Lexington Medical Center	West Columbia, SC
2004-2005	Health and Safety Instructor	American Red Cross	Columbia, SC

HONORS AND AWARDS

2015	Johns Hopkins University Leadership Education in Adolescent Health (LEAH) Nursing Fellow
2013	Johns Hopkins University Predoctoral Clinical Research Training Program Trainee
2012	Jonas Nurse Leaders Scholar
2006	<i>Magna cum laude</i> , Medical University of South Carolina
2006	Medical University of South Carolina Presidential Scholar
2006	Sigma Theta Tau International Honor Society of Nursing
2005	Lettie Pate Whitehead Foundation Scholarship
2004	Delta Omega Honorary Society in Public Health
2002	Palmetto Health Health Administration Scholarship
2002	Colonial Life Fellowship
2002	<i>Magna cum laude</i> , Florida State University
2002	Phi Kappa Phi Honor Society
2001	Florida State University Honors Program Finisher
2001	Kappa Omicron Nu Honor Society
2001	Golden Key International Honor Society
2000	National Society of Collegiate Scholars
1999	National Achievement Scholar

RESEARCH

2016-2018 The Influences of Coping Strategies and Social Support on Self-Care Behaviors among Young Women with Pelvic Inflammatory Disease. Ruth L. Kirschstein Predoctoral Individual National Research Service Award. 1F31NR016397. Role: PI. National Institute of Nursing Research (NINR). Total Direct Costs: \$87,620

SCHOLARSHIP

Publications

Tillman, J.L. & Mark, H.D. (2015). HIV and STI testing in older adults: An integrative review. *Journal of Clinical Nursing*, 24, 2074-2095. DOI: 10.1111/jocn.12797

Tillman, J.L., Trent, M., & Sharps, P. (In review). Coping and social support among adolescents and young adult women diagnosed with pelvic inflammatory disease.

Tillman, J.L., Hsieh, Y., Jett-Goheen, M., Solis, M., & Gaydos, C.A. (In review). Recent preventive health screening history among emergency department HIV self-testing kiosk users.

Presentations

Tillman, J.L., Robinson, K., Sharps, P., Wenzel, J., Alexander, K., & Trent, M. "My Body, My Business" – Diagnosis Disclosure in the Context of Pelvic Inflammatory Disease Self-Management. Poster presentation at the Society for Adolescent Health and Medicine 2018 Annual Meeting, Seattle, WA (3/14/18).

Tillman, J.L., Hsieh, Y., Jett-Goheen, M., Solis, M., & Gaydos, C.A. "Recent Preventive Health Screening History among Emergency Department HIV Self-Testing Kiosk Users." Poster presentation at the American Public Health Association Annual Meeting, Denver, CO (11/2/16).

Tillman, J.L. "Coping Strategies, Social Support, and Self-Care among Young Women with Pelvic Inflammatory Disease." Presented at the 2016 Leadership Education in Adolescent Health (LEAH) Meeting, Rockville, MD (5/18/16).

Tillman, J.L. "Older Adult Sexual Health." Online lecture for NR.110.305 Nursing Care of Older Adults across the Continuum, Johns Hopkins University. (Recorded in February 2015 and added to the course content).

Tillman, J.L. & Mark, H.D. "STI and HIV Screening in Older Adults: An Integrative Literature Review." Poster presentation at the 2014 STD Prevention Conference, Atlanta, GA (6/10/14).

Tillman, J.L. "Syphilis." Presented at the STD (Sexually Transmitted Diseases) Intensive Training, Norfolk, VA (1/29/14).

Tillman, J.L. "Herpes and Other Genital Ulcer Disease (GUD)." Presented at the STD Intensive Training, Norfolk, VA (1/29/14).

Tillman, J.L. "Healthy Relationships." Presented at the Delta Life Development Center, Columbia, SC (3/14/10).

Tillman, J.L. "Health Fair Coordination: How to Get Your Community Involved." Presented at the South Carolina Primary Health Care Association Outreach Network Meeting, Columbia, SC (8/28/09).

Tillman, J.L. "Let's Talk About Sex." Presented at the Delta Life Development Center, Columbia, SC (2/8/09).

EDITORIAL ACTIVITIES

Peer Review Activities

2018	Abstract Reviewer (Sexual and Reproductive Health Section)	American Public Health Association Annual Meeting
2018	Abstract Reviewer	Society for Adolescent Health and Medicine Annual Meeting
2016-2017	Abstract Reviewer (Population, Reproductive, and Sexual Health Section)	American Public Health Association Annual Meeting
2015	Ad hoc Manuscript Reviewer	<i>Sexually Transmitted Infections</i>
2015	Abstract Reviewer (Women's Caucus)	American Public Health Association Annual Meeting

PROFESSIONAL ACTIVITIES

Association/Advisory Board Membership and Leadership

2017-present	Association of Community Health Nursing Educators
2016-present	Society for Adolescent Health and Medicine
2010-present	American Sexually Transmitted Diseases Association
2003-present	American Public Health Association
2011	South Carolina Future of Nursing Task Force
2010	Outreach Council of the Diabetes Initiative of South Carolina

CURRICULUM VITAE

Part II

EDUCATIONAL ACTIVITIES

Classroom Instruction

Johns Hopkins University School of Nursing

Spring 2018	NR.210.610 Health Promotion and Risk Reduction Across the Lifespan, Teaching Assistant
Summer 2017	NR.110.810 Theory and Concepts of Health Behavior and Health Promotion, Guest Lecturer
Spring 2015	NR.110.305 Nursing Care of Older Adults Across the Continuum, Teaching Assistant
Fall 2014	NR.110.405 Public Health Nursing, Teaching Assistant
Spring 2014	NR.110.201 Human Growth and Development Through the Lifespan, Teaching Assistant
Fall 2013	NR.110.201 Human Growth and Development Through the Lifespan, Teaching Assistant

Virginia College (Columbia, SC)

Fall 2010	MED 1010 Medical Terminology, Instructor
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Kaplan Test Prep and Admissions (Columbia, SC)

2009-2012	NCLEX-RN Instructor
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ACADEMIC SERVICE

Johns Hopkins University

2014	Treasurer, Doctoral Student Association, Johns Hopkins University School of Nursing
2013	Public Relations Chair, Biomedical Scholars Association, Johns Hopkins University

Medical University of South Carolina

2006	Honor Council, Medical University of South Carolina College of Nursing
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Community Service

- 2017 Volunteer, JHU Visionaries vision screening at The Commodore John Rodgers School
- 2014 Faculty, Interprofessional Education Orientation, Johns Hopkins University
- 2014 Volunteer, Health Professions Recruitment and Exposure Program (HPREP)
Introduction to Graduate School Workshop, Johns Hopkins University
- 2014 Volunteer, HPREP College Prep Workshop, Johns Hopkins University
- 2013 Teacher, Community Adolescent Sexuality Education (CASE), Johns Hopkins
University (2013)
- 2013 Panel Speaker, MERIT Baltimore
- 2013 Speaker, Junior Biomedical Scholars, Johns Hopkins University
- 2010 Presenter, Science Technology Engineering and Mathematics (STEM) College and
Career Fair, Keenan High School
- 2009 Volunteer, National HIV/AIDS Testing Day
- 2009 Workshop Presenter, Delta GEMS (Growing and Empowering Myself Successfully)
Sexual Health
- 2006 Volunteer, South Carolina Area Health Education Consortium (AHEC) Pre-Nursing
Academy
- 2006 Speaker, Burke High School Health Sciences Class